

**ADMINISTRATION FOR THE DISABLED**  
**POLICY AND ORGANISATIONAL ISSUES**

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*Editor*

**T.N. CHATURVEDI**



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## FOREWORD

**T**HE Special Number of the Indian Journal of Public Administration for the year 1981 was appropriately devoted to the theme of administration for the disabled since the year was declared by the UN as the Year of the Disabled. The articles, surveys and other material like 'document' and bibliography included in that Number are now brought out as a separate publication of the Institute.

As pointed out by the editor of the *IJPA*, by the end of the century, the number of the disabled would be around 800 million. These would include the orthopaedically handicapped, the mentally retarded, the blind, the deaf, the victims of leprosy, etc. The handicapped cannot be left to fend for themselves and the society must help them. Thanks to the spectacular progress in science and technology, it is possible for the handicapped to overcome their handicaps and live a self-reliant and dignified life. But this requires that the spasmodic approach of the past should be given up and a planned and coordinated action evolved with the participation of state agencies as well as voluntary organisations to deal with different aspects of the rehabilitation of the handicapped people. Such an action should be backed up by a feeling of sympathy and compassion, a sense of social justice and responsibility, combined with management skill and technological capability.

This indeed is a field of public administration which has been neglected in the past in the conventional literature on public administration. In bringing out this volume on Administration for the Disabled, the Institute has perhaps blazed a new trail.

I would like to express my deep appreciation of the effort and the imagination shown by Shri T.N. Chaturvedi, editor of the *IJPA*, and his staff in making it possible for the Institute to bring out this publication.

New Delhi  
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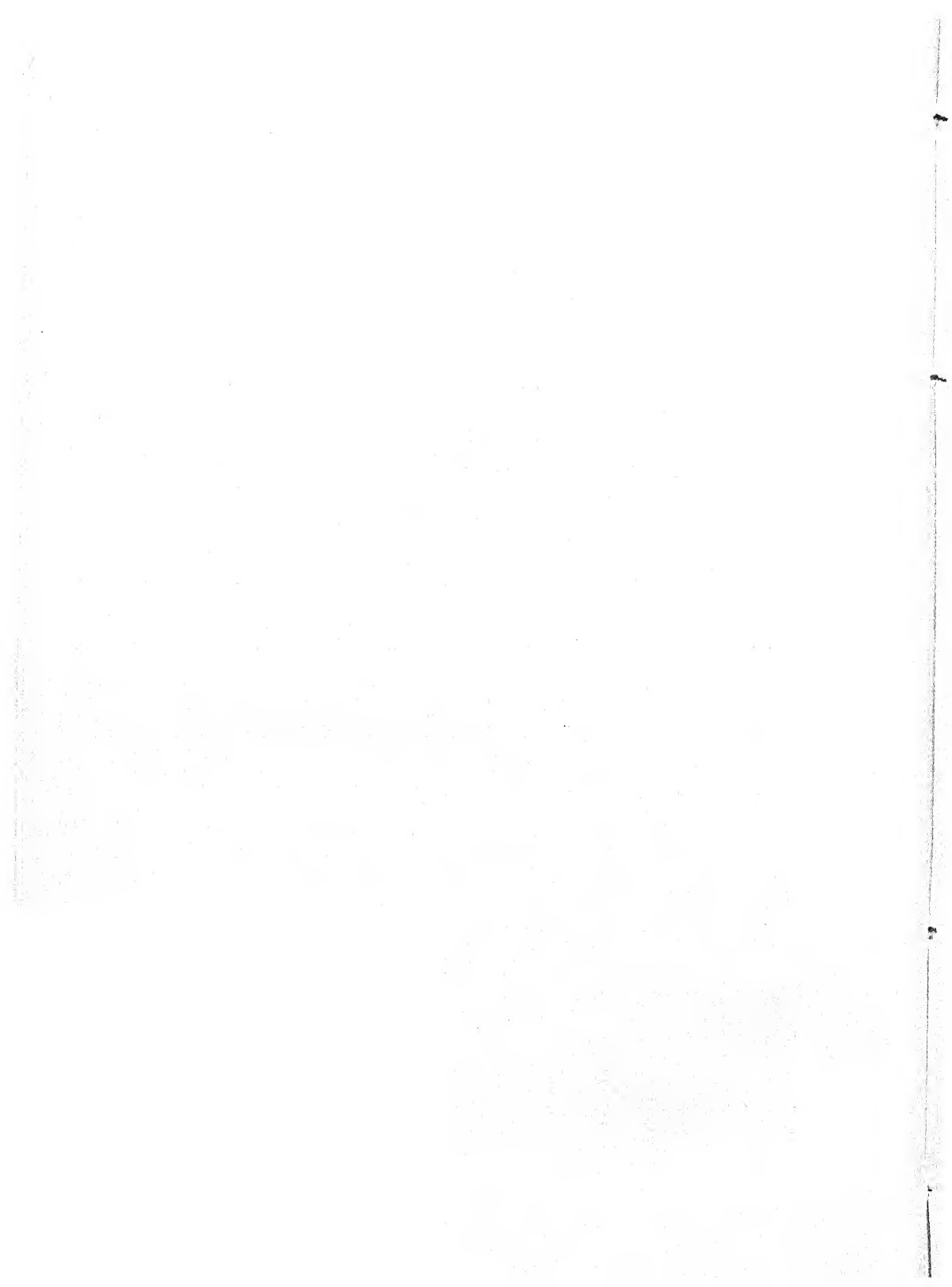
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## PREFACE

WE have tried to discuss in this volume the multiplicity of issues relating to the suffering and the sense of deprivation of over 450 million people of both sexes and all ages spread all over the world. This figure is only an intelligent guess, for nobody yet knows the exact number. Also, as it happens in several other areas of privation, the disabled are known to be more in the third world countries and, in these countries, they are more among the non-privileged or the disadvantaged and poorer classes. It is further known that within these countries and within these sections, it is the children that predominate.

Sobering and frightening as these pieces of statistical information are, what seems to be in store for mankind in the future is still more sobering and terrifying, namely, that by the end of the century the disabled will be no less than 800 million people, that is, about 120 million more than the present population of India! Another aspect of the problem of the disabled is that much of what is preventable is allowed to continue and increase in magnitude by neglect, ignorance, apathy, and sheer cussedness. Similarly, the handicapped suffer not only from a physical deformity and sense of inferiority, but they face constantly the agony of impairment and, very often, cruel treatment by their own people, who ought to know better, and discrimination by society whether in education, employment, social life, or contractual rights.

We feel that this book provides a challenge as well as some guidance to the contemporary society which prides itself as one which is both human and humane. It will help to extend the frontiers of knowledge and understanding of an area hitherto neglected and will act also as an appeal to social conscience through pointed, objective and scientific discussion.

Programmes and techniques of rehabilitation of the handicapped are by now fairly well understood and governments and international bodies have charted policies and approaches in this respect. But what apparently lacking is the organisational effort, political will and financial resources. It is true that, as Gandhiji said of poverty, the exact number involved may not matter, put against the urgency of starting on some measure or the other for amelioration. But in the absence of a really firm knowledge of the numbers involved



and the variety of disabilities, the rehabilitation measures become no more than a demonstrative token, not a realistic step towards relief with all its financial, administrative, and social implications.

It is such a broad outline that this book attempts to cover. We begin with the articles by various distinguished contributors and have arranged them in a manner that the general policy issues and programmes come first, followed by discussions of specific handicaps and their problems of rehabilitation. Thus we have the blind, the deaf and the dumb, the mentally retarded, the leprosy afflicted, the orthopaedically handicapped, etc., and we have several articles mentioning, in passing, about lunacy, drug addiction, and the like. We have also articles discussing issues such as the transport problems of the orthopaedically disabled. Towards the end of this section, we have a couple of notes, one dealing with a unit manufacturing artificial limbs and the other describing the official survey in India now under way to estimate the number of the disabled that may be there in the country.

With this introduction to serve as a backdrop, we take up the articles for some detailed comment. As we have said above, we deal with those articles first which discuss policy matters and we have Thangavelu asking for a policy for the welfare of the disabled, which should be at once humanitarian and economic and which should include education, health and medical services, vocational training and placement of the handicapped in gainful occupations, and a special provision to deal with the social problems of the severely handicapped.

Thangavelu then gives a breakdown of the programme for the disabled under the policy frame, both institution based and home based. He elaborates the services that will be required under this programme, the training that will be imparted, the feedback that will be required and the effort that will be needed to link services with cost. He also discusses the appropriate administrative arrangement for delivering the services and for involving the people in the entire programme.

Ramalingaswami takes up the problems of the disabled in India and warns the country against 'zerox copying' of technologies and rehabilitation development techniques in the more affluent countries. He pleads for early detection of disability, especially among children, and also underlines the efficacy of prevention of disability over subsequent efforts at cure. More than the handicap itself, Ramalingaswami points out, it is the climate of deprivation, coupled with social ostracism that affect the impaired people and it is factors such as these that lead so many of the disabled to a life of beggary and servitude. Ultimately, therefore, he says, the safe way to reduce the



extent of severity of disability is the awakening of the society itself and when, in the process, the rural poor also become aware of the facilities that are available to them.

Arie Halachmi, writing about disability in America, deals with the paradox in that country where an economy-conscious administration tries to cut expenditure on social services in contrast to the public interest in the problems of the disabled, and the ambivalence resulting from this national dichotomy. He specifically mentions four types of paradoxes in this respect and says that unless there is a change in society as regards its basic values and approaches, the effects of the so-called public policy towards the disabled may be just marginal and temporary. It is interesting to read here about the US administration providing help to the disabled not on the basis of need but rather as a function of the interest, resources, and ability to get organised by all those other than the disabled themselves. We have to concede that such a slant is not exclusively in the United States about which Halachmi writes; this is increasingly felt in other countries also such as India where, as we have mentioned earlier, it is more the vocally alert and articulate urban section that benefits, leaving the needy poor in the villages largely unattended.

Nana Chudasama in his article wants society to break the various barriers that wall in the disabled such as the architectural and transportation obstacles; unrelated medical criteria used in job requirements; and the attitudinal barriers which, according to him, are the hardest to topple. He is very clear that unless we integrate the handicapped into every aspect of society, we will be permanently keeping justice itself 'disabled'.

The next three articles, by N.R. Inamdar and Nalini Paranjpe, H.J.M. Desai, and M. Natarajan, trace the evolution of the administrative set-up for the service of the handicapped in India. They analyse the present structure and spell out the inadequacies.

According to Inamdar and his associate, the welfare services for the handicapped in the country are hamstrung by inadequate finance. Allocations are regarded as 'consumption expenditure', with the connotation that they mean a drain on the economy. The Third Plan, no doubt, called for investment in 'human resources' but this is not seen in practice and the welfare schemes of the handicapped are still in essence seen as measures of charity. He, like Thangavelu earlier, calls for a cost-benefit analysis of the different services so that the meagre available resources can be put to the best use. Desai too feels that our existing organisational structure for dealing with the problems of the disabled is not sound; there should be a fresh





look both at what the government does and what the voluntary agencies do. According to him there should be total decentralisation of the responsibility for looking after the disabled and it should go down to the district level. The district authorities should not only be given the necessary responsibility but also be empowered to impose a small levy from the proceeds of which they may meet a part at least of the cost for providing rehabilitation services. Further, he wants managerial techniques to be applied to the delivery of services and these services to be tuned in a manner that will render the disabled fully productive. Legislation may go some way in several respects but legislation, in order to be effective, should be based on a coherent national policy and a national plan, both sanctioned by Parliament and effectively supported by the people. Natarajan gives a detailed chart of a national organisation for the disabled, giving out the functions broadly at each level: the country, the state, the district and the village. He wants a committed philosophy for the rehabilitation of the disabled which should form part of the constitution of the country. He also writes about the need for proper devolution of responsibility and wants the country to realise that rehabilitation of the handicapped is a service oriented activity; the strategies and tactics should therefore have to mobilise certain social forces in order to reach the goal. This, in turn, requires the active participation of community leaders in the service organisations and the involvement of voluntary agencies in order to provide the emotional and popular drive to the programmes sanctioned, initiated and monitored by the official machinery.

Continuing on the same lines and stressing on the developments in India are a series of six articles by Afzal Jehan Friese, S.D. Gokhale, P.P. Trivedi, G. Ravindran Nair, S.K. Verma and Anil Chawla, and S.R. Mohsini. What is in common with all these writers is their sense of hope that the disabled may have a better future if only we marshal the resources at our command and utilise them in a purposeful manner. They also feel that we have to shed a lot of our accepted beliefs and notions about the problems of rehabilitation of the disabled. For instance, Afzal Friese points out that 'love and dedication' alone will not do; these should be supplemented by ascertaining the professional skills and competence of the needy disabled, their own attitudes and the desired attitudes for specific jobs, etc. Also, we must realise that the achievements by the disabled

- are not dependent on their disability but on the opportunities provided to them for learning and development of skills and attitudes. The economic costs of rehabilitating the disabled are certainly high, the writer concedes, but the social costs of their remaining disabled are higher still. Gokhale stresses that rehabilitation should be closely



related to the total environment of the disabled persons, for there cannot be a piecemeal approach. A farm labourer, for instance, who has his legs amputated should not be made to discover that the artificial legs provided to him are of little use in the paddy field where he is supposed to go back to work. This calls for application of appropriate technology in rehabilitation in a rural setting like that in India. The rural society, according to Gokhale, has certain inherent strengths such as close inter-personal relations and a humane attitude towards the affected. There are handicaps also inasmuch as superstition, ignorance, etc., exaggerate and stigmatise the disabilities. P.P. Trivedi writes about the scope for prevention of handicaps, especially in rural areas, provided the policy making organisations, like the Ministry of Health and the Department of Social Welfare, have a coherent plan for the purpose and they have a medium of dialogue between each other on the same wave-length. She also points out the undesirability of concentrating the services in isolated institutions, especially in matters of education of the disabled. She feels that the disabled themselves do not want to be looked down upon or pitied upon. The community effort, therefore, should be to restore self-respect among the disabled which, in essence, points towards self-employment so as to draw out the relevant skills of the disabled and also help them to retain their affinity with their normal living conditions.

Ravindran Nair, writing on the role of the voluntary organisations in India in the service of the disabled, brings out the change in emphasis in these services over the years. He also points out that some states have a greater momentum in social welfare movement than others and he mentions Maharashtra, Tamil Nadu and Gujarat in this respect. There is a concentration of the voluntary institutions also, especially in the metropolitan cities like Bombay, Delhi, Calcutta and Madras. The voluntary institutions, he says, have done pioneering work in several spheres of social rehabilitation of the handicapped but they, at the moment, suffer from lack of resources and lack of adequate trained manpower. In any case, even with all the institutions put together, their services have only touched the fringe of the problem. What these agencies have achieved and for which they deserve full credit is the social awareness and the social awakening that they have been able to create, however small this effort may seem to be.

S.K. Verma and Anil Chawla have, likewise, drawn attention to the correlation between disability and socio-economic disadvantages and have said that no single intervention at any one stage would solve what is a complex and multifaceted problem of the disabled. It is, nevertheless, important that the community should accept the



basic right of the disabled to human decency and to a life of productivity and fulfilment whether his handicap is mild or severe, single or multiple, incurred at birth or later in life, whether he lives in an urban or rural environment, or whether his family has income or he is poor.

S.R. Mohsini writes on the emerging concept of welfare of the physically handicapped and notes the changes that have occurred in this area over the years and, like several of the writers referred to earlier, stresses on taking into account the socio-economic environment while caring for the disabled. He notes the advancement made in medical, pedagogical as well as in behavioural and social sciences generally that has come to the help of disabled persons. He also draws attention to the UN document on rehabilitation, elucidating the new approach to the problems of the handicapped and the new concept of their welfare. It is part of this new approach, he says, that the physically handicapped is now recognised as an emotionally disturbed person and that is why he has a special claim on society for sympathy and constructive help. The UN document expresses the faith that the handicapped, given the right opportunity, may turn out to be an economic asset to the community instead of being a burden on himself, on his family, and on the state. This is the goal that we have to strive for.

There are two articles, one by Bata K. Dey and the other by Mukkavilli Seetharam, on the constitutional and legislative rights of the disabled in India. Dey discusses the reservation of jobs for the disabled and also lists the provisions in the constitution taking care of the disabled, especially the blind, along with the scheduled castes and scheduled tribes. According to him, the rehabilitation programmes of the handicapped, however well intentioned, cannot be in generic terms : they should be tailored to the specific requirements of particular categories of this community. However, he is conscious of the fact that the state, with its limited resources crying for distribution among competing claims, cannot hope to fulfil all the needs of the handicapped. In these circumstances, the state can at best be only a catalytic agent. Total help to the handicapped can result only when all the concerned sections of society are in full participation in the effort to meet their needs.

Seetharam lists the several laws under which the disabled can expect state help, but he feels that almost all of them need to be amended in terms of the changed social climate and the specific requirements of the handicapped. For instance, the Lunacy Act calls for a thorough change and so do several others. Most of the existing laws were drafted at a time when the obligations of the state towards society were limited and when there were no demands on the



state by the specific classes of the handicapped. These have changed now and, therefore, according to the writer, the need for corresponding changes in the laws. This is a matter meriting consideration of the policy makers. But laws must have corresponding institutional arrangements for their effectiveness.

There is one article in this issue which discusses the transport problems of the disabled. This is a study of the rebus scheme in Hong Kong. Dorothy Chan traces the beginning of the scheme, its present coverage, its viability and its potentialities. According to her, the rebus service has a vital part in meeting the needs of the disabled who normally face a lot of problems arising from their own difficulty in being mobile and from the lack of suitable transport facilities for them. She feels that such a service as in Hong Kong can be made useful and also run at a reasonable cost. Though the problems of Hong Kong and of a continental country like India differ in almost all respects regarding commutation of their people, Dorothy Chan's article highlighting the advantages of a special service is useful to us insofar as it draws our attention to a particular type of service to the disabled which has more or less escaped our attention.

Miron Mushkat and Meenakshi try to give some acceptable standards for measuring disability. Mushkat draws heavily on medical sciences where objective tests have been in use for long to measure each type of disability and its intensity. He is of the view that with suitable adaptations, the Index of ADL, the Measure of Incapacity for Self-Care, and the Maryland Disability Index, etc., which have proved themselves effective in a wide variety of contexts, can be made use of for measuring disabilities also. No doubt, more research is required before adequate specificity is brought about in this regard but it is possible to agree with Mushkat that we should step outside the rather narrow domain of subjective measurements and find a way to bring disability also into a recognisable field of identification and assessment with greater exactitude.

Meenakshi writes about the ambivalence in the definition of the handicaps and she also agrees that in several respects the conventional definitions reflect personal judgements. According to her, 'physical fitness' is itself a relative term. It is supposed to measure functional capacity of an individual for a task and it may have no meaning unless the task, for which the fitness is to be judged, is itself specified. Similarly, the term 'normal' is not a statistical concept but is based on available subjective observations or impressionistic consideration. From here, Meenakshi traces the impact of such allegedly loose definitions on social policy and rehabilitation programmes of the handicapped. When we think of 'who is going to define' we find



incompatibility between the medical and the administrative defining systems. The clinical definitions are designed for large groups of people and though they may be useful for clinical analysis they become difficult to use in the administrative context. Confusion arises when administration tries to adopt the medical definitions for its policies and programmes without simultaneously bothering to know whether the two systems of definitions are compatible in their results. This is an important area for social research.

Dealing with specific areas of disability, Seeta Sinclair, Anima Sen, Nandini P. Divatia and Narayana Reddy write on the mentally retarded. Thomas D. Watts deals with the needs of the aged disabled; Miriam Itteyerah and Vibha R. Gupta and Sushma Batra write about the blind; Surrendar Saini takes up the problems of the deaf; and J.M. Mehta discusses the rehabilitation of the leprosy disabled. Seeta Sinclair, writing on a possible future for the mentally handicapped, elaborates a plan discussed at a seminar under the joint sponsorship of the Directorate of Health Services (India), the World Health Organisation, and the All-India Institute of Medical Sciences in 1978-79. According to her this plan covers medical services, education and vocational training, employment, insurance, social security, etc., for the mentally handicapped. The plan lays considerable stress on prevention of mental disability by adequate supervision of deliveries. This is important since it is known that birth trauma and anoxia are responsible for about 25 per cent of all cases of mental disability. Seeta Sinclair also pleads for a national plan for the mentally handicapped and for its proper implementation, involving the concerned departments of the government both at the national and state level and also of the parents of the affected. Monitoring and evaluation of all service programmes is essential according to her and there should be coordination at the central, middle and peripheral levels so that the plan's implementation may be really useful to the disabled.

Anima Sen takes up the education of the mentally retarded and she holds that in this specific context education is not just reading and writing but the patient's all round development, taking into account that the patient has limited learning capacity; he may also be incapable of having the normal social and emotional relationships with the peer groups or with others. Normalisation of the handicapped in this context requires different types of educational methods and the curriculum provided for the mildly retarded will not suit those with severe retardation. The latter will need the services of special staff. Education, to be effective, should be started early enough in the patient's life, for it is found that the extent to which the young patient has opportunities to interact with the changing



environment directly affects his development also. In the process of such an education, it is important to develop the self-image of the retarded. The severely retarded may have to be hospitalised but the families concerned should also be involved in the care of such patients. In conclusion, Anima Sen observes that in India it is the adult retardates that get a raw deal from the authorities and the community so far as their educational needs are concerned. Neither the private organisations nor the state, she complains, have dealt adequately with the problems of these retardates.

Nandini Divatia wants the mentally retarded to be given opportunities of work in appropriate industries and business organisations. This, of course, excludes the severely retarded. However, according to the writer, more than 50 per cent of the mentally handicapped here are with IQ varying between 50-75 and they can be trained and made useful members in society. Their educational method consists of vocational training through sheltered workshops and then, according to their ability, placement either in appropriate establishments or in self-employment. The mentally retarded should also have the guardianship arrangement, the writer emphasises, *i.e.*, a recognised legal relationship between a specified competent adult on the one hand and the 'ward' on the other, in order to take care of the legal rights of the latter.

Narayana Reddy puts emphasis on the family as the base of rehabilitation of the mentally retarded. He also points out that rehabilitation depends on many factors other than just the intelligence of the retarded. He agrees with the other experts that with proper treatment and education, the mentally retarded can be made self-supporting. They should be helped to understand their own limitations first and taught about it through concrete meaningful exercises. He warns that parents of the retardates should also be among the first to recognise the limited achievement potential of their children and they should reconcile themselves to limited goals. This will avoid frustration and help a more positive effort towards ameliorative and rehabilitative approach on their part. Early introduction of counselling and guidance programmes to the members of the family will be useful than at a later stage when behavioural patterns of the retarded may have been fixed. Reddy also feels that rehabilitation programmes should be made as simple as possible and as cheap as possible so as to be available to the common man. It is here that the state as well as the philanthropic instincts of society and the sense of social responsibility on the part of industry and business have a definite role to play.

Thomas D. Watts considers the worldwide, growing, aged disabled population as a challenge to government policies and, may be, to the overall commitment of governments to egalitarian goals.



Even the affluent western states, with all the resources at their disposal, he says, are finding it increasingly difficult to support the growing number of dependent population in their midst. On the other hand, the aged disabled are hampered to put forward their claims because of their being both aged and disabled. Watts, no doubt, speaks of the aged disabled in the United States but cites several evidences of their growing weight in the economic and social calculations of India also. He makes a contrast between the institutionalised help in America and other affluent countries and the home based, non-institutional service in countries such as India. He commends the latter in the Indian context for, according to him, such services are not only less expensive but more humane.

Miriam Itteyerah and Vibha Gupta have a technical article on the blind which also touches upon the socio-economic implications. By diagnosing the extent of blindness and the degree of blindness by scientific methods, they try to find out how the blind may be recommended for jobs in specific industries or other work units taking into account the job seeker's perceptual capacity. This, they feel, will help to promote employment opportunities for the blind without affecting the productivity in the units where they are likely to be employed.

Sushma Batra writes about a study that she made on the integration of the blind persons with the normal. This study aimed at analysing the factors which increased or hindered the integration of the blind with society. Her finding is that the disability of the blind is not just physical; the greatest hurdle in their integration with normal people is the misconception prevalent among them about the blind. Most of it is the result of ignorance. But once the people with normal vision are put in contact with the blind, Sushma Batra has noted a very positive attitude towards each other which, according to her, augurs well for a large scale attempt at integration. She also asserts that even in her small sample, integration proved most successful in cases where the blind had self-confidence and where they retained their will power for integration. For a more homogenous rehabilitation process, this approach needs to be further explored.

About the deaf, Surrendar Saini says that they are a neglected lot. The services to them are *ad hoc* and confined to urban areas. Much of the deafness, according to the writer, is preventable by early detection, diagnosis and proper treatment and it is advisable that maternity and child welfare centres should be equipped to cater to these aspects of the people's health problem. The economic rehabilitation of the deaf is also possible by proper training through special technical institutions by the different states. This kind of disability, somehow or the other, is apt to be ignored as it has not



the same visual impact as many other kinds of debilitating handicaps.

The leprosy patients, according to Mehta, are the most neglected because of the stigma attached to the disease which brings about an unsympathetic public and even official attitude. Though the government policy is to assist the leprosy patient, this does not work in practice due to lack of personnel and lack of motivation. On the other hand, rehabilitation in leprosy is easy. According to Mehta, with proper training, a moderately deformed patient can perform several jobs efficiently. But it is the stigma that comes in the way as nobody wants to do anything with even a cured leprosy patient and it is the stigma again that drives a large number of patients to beggary and anti-social activities. Altogether this is a gloomy area, says Mehta, and he sees hope only when there has been a radical change in our thinking and attitude towards this section of the handicapped. Legislation may be of little use here and the tragedy of leprosy is that even those in the community who ought to know better adopt a very negative attitude towards the leprosy patients. Leprosy, concludes Mehta, is a highly misunderstood disease. This is all the more a pity, as from Gandhiji onwards, both social workers and medical experts have tried to explain that the disease is curable and is not infectious except in the case of children. More light and action are needed in this area for creation of a right kind of climate of social opinion.

The articles included here delineate many unexplored areas for research and experimentation. They indicate the desired linkages that have to be established between different branches of science and humanistic as well as social sciences if administrative policies and strategies have to be devised and organisational efforts mounted for amelioration of human suffering. The need for community understanding and support as also the need for close cooperation between voluntary agencies and state organisations have been highlighted. The theme of the disabled and the handicapped is not there just to evoke pity but to activate social empathy and action. The various contributors underscore the many areas of cooperative endeavour and understanding as well as the necessity for optimisation of resources through a scientific approach and appropriate managerial techniques. The book aims to place the entire gamut of issues of the problems of the handicapped in a wide perspective and will be of interest and use to all sections in society, and not just to those directly concerned with public administration and its study.

Following the articles by the learned contributors, we give surveys about the disabled from a dozen countries, both developed and developing, and they show that though the degree of the problem





differs, in their essential nature and rehabilitation the issues are very much similar; it is almost always the question of meeting the demand for rehabilitation with the limited resources in men and money. They also indicate, though briefly, the possibilities of regional cooperation among the third world countries with tight budgets and limited personnel. There is also the suggestion here that institutionalisation may not be the answer to all problems of rehabilitation.

The next section is about the rehabilitation attempts by the various state governments in India. The foremost inadequacy mentioned in these reports is that the states concerned do not have with them any firm data about the number, the range, the intensity and the exact problems of each type of the disabled within their jurisdiction. The result is that the steps they have taken towards rehabilitation tend to be ritualistic with no touch of realism. For instance, the uniform 3 per cent reservation of jobs to the handicapped is meant to be really an indication of social concern and sympathy but, unfortunately, the process of implementation seems to be tardy and even disappointing. The states do not always have a clear idea of the spread of the handicaps between the rural and the urban areas; the result is that most of the service institutions and medical facilities are in urban centres though it stands to reason that those who really need these services are in the villages. Similarly, the cost of rehabilitation has not entered the calculations of such services, for most of the users of the services as at present are the well-to-do, whereas those who are in dire need of these services are forced to go without them. Again, it is in the villages that prejudice and ignorance prevail and the disabled therefore are made to suffer more than what may be their share if enlightened help and guidance are forthcoming. If we admit that much of the disability now prevalent in the villages is preventable, it is obvious that the pre-natal and the post-natal care should be concentrated there and the organisation of these services must be tilted to the rural rather than the urban areas as a policy of deliberate corrective discrimination.

In the section 'document', towards the end of the book we give the full text of part I of the report (1981) of the Director-General, ILO made available to us by their Geneva office recently. This gives at one place the essence of rehabilitation steps taken by various countries and looks forward to what may be possible in the future with these governments and non-official agencies working together and with the help of specialised international bodies like ILO.

We bring the book to a close with a bibliography of selected books and articles on the handicapped and this lists over five hundred



items, with several of the citations from within India. This will be of interest to social workers, research students and policy makers as well as administrators, as a source of ready reference.

Now it remains for me to thank all those who have helped to make this volume what it is. They run into a large number as can very well be imagined and among them the eminent contributors come first to my mind. I take this opportunity to express my gratefulness to them. About the officials and official sources, in India and abroad, who have come forward to extend their help to us, we have acknowledged their contribution at the appropriate places. Even so, I reiterate my thanks to them all here also. We are wholly indebted to ILO, Geneva, for the document which we publish at the end of the book.

Shri Mohinder Singh and Shri R.N. Sharma of the IIPA library have compiled the bibliography and they have been helped in their effort by Shri A.C. Tikekar, (I/C), University Librarian, Bombay University. I thank them.

Shri N.R. Gopalakrishnan, in charge of the Publication Division in IIPA, has helped me in editing this volume and he and his team have worked hard in the press to bring it out in good time. I am grateful to them all.

I shall also like to thank Shri P.R. Dubhashi, Director, IIPA for providing me the necessary facilities and for contributing a foreword to the volume.

This effort of ours is a further indication that the range of administration is wider than what is conventionally accepted; public interest on a topic such as the one we handle here is surprisingly wide. We have brought together here experts from different disciplines and domains of knowledge for creative interaction and it reflects the interdisciplinary nature of the problem and our own approach to it. We believe, with all humility, that through this book the IIPA has made its contribution towards a new dimension of public policy and public administration. This is also our modest contribution towards a more fruitful and lasting observance of the International Year of the Disabled. We initiate a dialogue here for continuing action in this field of immense social significance.

*New Delhi,  
November, 1981*

T. N. CHATURVEDI  
*Editor*

**INTERNATIONAL YEAR OF  
THE DISABLED PERSONS  
1981**



*The Logo represents two people holding hands in solidarity and support of each other in a position of equality.*

**FULL PARTICIPATION AND  
EQUALITY**

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## IYDP

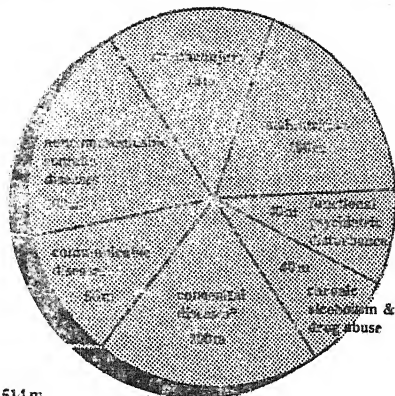
“By proclaiming 1981 as the International Year of Disabled Persons, the General Assembly of the United Nations aimed at focusing attention on the enjoyment by disabled persons of rights and opportunities in order to ensure their full participation and integration into society. The effort to find solutions to the problem of disabled persons should be an integral part of national development strategies. There is thus a need to secure the participation of all Member States, as well as relevant governmental and non-governmental organizations in the preparation and implementation of the programme of the International Year of Disabled Persons.”

KURT WALDHEIM  
*Secretary-General of the United Nations*

# The global picture

## WORLD INCIDENCE OF DISABILITY

(in millions)

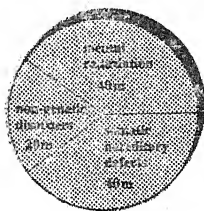


Total = 514m

The accepted minimum estimate of the magnitude of the disability problem is that at least one in ten children is born with, or acquires, a physical, mental or sensory impairment. The data are very incomplete; estimates rise to 15 or 20% depending on definitions used and conditions included. Rehabilitation International's figure is 500 million; over 2/3 of these live in developing countries, mostly without any rehabilitative services.

\* eg: back disorders, heart conditions, epilepsy, arthritis, etc.

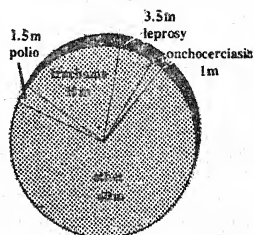
### CONGENITAL DISEASES



Definition: diseases existing at, and usually before, birth, regardless of cause. Somatic hereditary defects: physical imperfections genetically transmitted from parent to offspring, eg club foot, cleft-lip, spina bifida, blindness, deafness, muscular dystrophy, genitourinary malformation, cystic fibrosis. Non-genetic = non-hereditary disorder.

### COMMUNICABLE DISEASES

Definition: diseases which can be carried from one person to another, directly or indirectly. Where people live in a deprived social environment and in insanitary conditions, as in poor, densely-settled urban areas, the risk of contracting a communicable disease rises considerably.



## SPECIFIC PROBLEMS OF DEVELOPING COUNTRIES

The incidence and the serious impact of impairment of disability and of handicap are greater in countries in the earlier stages of economic and social development than in the more advanced countries. This situation is a consequence of factors that must be recognised and taken into account in planning to support programmes for disability prevention and rehabilitation in these areas. Some of the most important are:

- (a) A high proportion of overburdened and impoverished families;
- (b) Populations with a high proportion of illiteracy and little awareness of routine measures for health, education and welfare;
- (c) Absence at all levels of people, from villagers to senior officials, of accurate information about disability, its causes, prevention and treatment;
- (d) Insufficient programmes for the prevention of conditions that cause impairment, and inadequate services to respond to impairment and disability;
- (e) Obstacles such as lack of money, geographic distance and social barriers which make it impossible for many children to take advantage of services that may exist;
- (f) Use of limited available resources to operate services which are too highly specialised to reach most children who need them;
- (g) The absence or weakness of an infrastructure of related services for health, education, welfare and vocational preparation;
- (h) Low priority in development strategies for activities related to disability prevention and rehabilitation.

## Administration for the Disabled : Policy and Organisational Issues

M. Thangavelu

THE THIRTY-FOURTH session of the United Nations General Assembly, in adopting a resolution on the International Year of Disabled Persons—1981 (IYDP),<sup>1</sup> invited member states to consider activities to promote the care of the disabled at national level in conformity with the culture, customs and traditions of each country. Traditionally, in developing countries such care has been the responsibility of the family and/or private organisations. With the emergence of the concept of welfare states, the trend in the planning and administration of services for the disabled is more and more towards a centralised approach to the problem. This change has been influenced by experiences gained in developed countries in the rehabilitation of the casualties suffered in World Wars I and II. Though this approach may appear to be a satisfactory one for governments in managing the rehabilitation of those maimed in battle, the implementation of such a centralised strategy for all of the disabled in the country is beset with a number of constraints, ranging from lack of financial resources to neglect of responsibility on the part of the community, the family and the disabled themselves, which may result in a state of pathetic dependence on the society. Instead of the disabled being in a position to enjoy a status of dignified partnership in socio-economic development, they are considered a liability, at the receiving end of social concessions of a charitable nature. Hence, an attitudinal change is called for, transforming this approach from one of sympathy to one of empathy, where the emphasis is on providing opportunities for developing the abilities of the disabled for their own social welfare and happiness. Viewed in this context, in formulating a policy for administration and implementation of a programme for the disabled, the aim should be to identify and enhance their latent abilities in order that they may maximise their social contribution through leading an improved quality of life and having a new sense of self-reliance.

Another significant development in recent years has been the importance

<sup>1</sup>International Year of the Disabled (1981), United Nations General Assembly, Thirty Fourth Session, Third Committee, draft resolution A/C. 4/34L. 57, 27 Nov. 1979.



of prevention as an integral component of any rehabilitation programme. If we analyse the causes of disability, apart from congenital factors (which also may be prevented through genetic and ante-natal counselling), communicable and non-communicable diseases obviously contribute to functional and social limitations. Poliomyelitis is now a disease of the past in many developed countries, where immunisation has long been given against the disease. The incidence of stroke is also registering a downward trend with intervention instituted early against hypertension. The decrease in domestic and traffic accidents through prevention and public education and the provision of facilities for prompt first aid and emergency resuscitation measures have considerably reduced morbidity as well as mortality. Meticulous medical management has promoted early rehabilitation of accident victims. A little attention to environmental conditions, life styles and behaviour will pay greater dividends through lessening physical and emotional disabilities.

These are the considerations which prompted WHO<sup>2</sup> to formulate a comprehensive programme for disability prevention and rehabilitation, emphasising the importance of intervention aimed at reducing the occurrence of disability or at least diminishing its impact on the individual and the community.

### POLICY

In formulating a policy for the welfare of the disabled, both humanitarian and economic considerations should receive attention. The humanitarian aspects should promote the dignity and self-reliance of the disabled, and the economic aspects should provide for development of skills and unhampered opportunities for them to lead a productive life in the community.

While rehabilitation of the disabled may receive priority consideration, the policy should also be aimed at intervention measures for prevention as well as at those rehabilitation services which require a multidisciplinary and multisectoral approach through the coordinated medical, social, educational and vocational measures for training or retraining the individual to the highest possible level of his/her functional ability.<sup>3</sup> Hence, the following might be the basis for formulating a national policy for community-oriented disability prevention and rehabilitation services:

- (i) Involvement of different ministries and departments to ensure coordination.
- (ii) Participation and cooperation of various departments.

<sup>2</sup>World Health Organization, Twenty-Ninth World Health Assembly, Reports on Specific Technical Matters, Disability Prevention and Rehabilitation—A 29/INF. DOC/1, 28 April 1976

<sup>3</sup>WHO Technical Report Series, No. 419, 1969.



- (iii) Creation of community awareness and education of the public on prevention of disabilities, and promotion of self-reliance in the management of the disabled through training and services at the community level.
- (iv) Encouragement to the disabled to express their needs and to be trained in a family or community setting.
- (v) Integration of the disabled into the mainstream of community life through making them economically independent and equal partners with others in social development.
- (vi) Development of institutional facilities for referral services at appropriate levels of health care for the management of difficult cases.
- (vii) Training of the disabled, family members and community volunteers.
- (viii) Optimisation of the utilisation of resources through an in-built system of monitoring and evaluation.
- (ix) Promotion of accountability and credibility of organisations engaged in rehabilitation activities.

These considerations should prompt an approach in policy formulation in which the disabled themselves would have a say in the decision-making process. Education and training should enable them, their family and their community to articulate their needs and thus assist the experts and professionals in assessing the over-all community and population needs for rehabilitation services. Involvement of the disabled and the community in the process of policy making should thus be ensured. Facts presented by the disabled, the community and the voluntary organisations engaged in rehabilitation services should permit the formulation of a viable policy. Task force established for the study and analysis of social and environmental conditions; of the attitude of the community towards the disabled; of communication and of physical and cultural accessibility; of education, training, health and medical services, vocational training and placement in gainful occupations would substantially contribute to policy formulation. Special provisions should be made in the policy statement to deal with the social problems of the severely handicapped—problems such as residential accommodation services, including nursing, civil rights, ageing, etc.<sup>4</sup>

The government in elaborating the policy for prevention of disability and rehabilitation (which, as mentioned, should promote self-reliance, economic independence and social integration of the disabled in the community), should retain for itself the privilege of maintaining and operating a system of surveillance and assessment of the magnitude of the problem

<sup>4</sup>Federal Register, Department of Health Education and Welfare (USA), *Vocational Rehabilitation Administration*, Vol 31, November 9, 1966.



in the country, guiding multisectoral coordination, monitoring the implementation of the national programme, guaranteeing resources for decentralised implementation and promoting research into and development of appropriate technology in rehabilitation aids.

### PROGRAMME

So far, programmes for the disabled have tended to be institution-based and delivered by highly specialised categories of rehabilitation personnel—physical medicine experts, physiotherapists, orthotic and prosthetic technicians, occupational therapists, speech therapists, vocational counsellors, psychologists, social workers, etc. An alternative to this approach has been elaborated by the WHO and is undergoing field trial. In it, community leaders are to be trained in making surveys of the disabled, in guiding those requiring health care through the various phases of medical rehabilitation, giving them vocational training and integrating them into the main stream of life in society. This approach is community-oriented, is related to the resources available, promotes self-reliance and enlists the participation of the disabled, the family and the group. The draft WHO manual for the 'Training of the Disabled in the Community' emphasises that the programme for the disabled should make use of local manpower and technical resources. "The system for referrals and supervision will be set up with the aim of involving present institutions for the disabled and other community and regional level services, making them more involved and active in solving the problems facing the disabled in their communities".<sup>5</sup>

A programme of such a comprehensive nature has the following components: services, training and research.

#### *Services*

The primary target will be the disabled and their families. The objectives are to reduce disability at the community level and provide for greater coverage of the population with rehabilitative services and social integration of the disabled. The services will be made available as near as possible to the underserved in rural areas and to the underprivileged. Other objectives are promotional and developmental in nature. Public understanding of the serious effects of disability in retarding socio-economic development will be fostered through education on prevention and demonstration of the feasibility of functional and social restoration through rehabilitation. The programme will be supported by studies and research.

In the provision of these services, a motivated family or a group should

<sup>5</sup>Training the Disabled in the Community, A Manual of Rehabilitation for Developing Countries. Part A, Guide for Policy makers and Planners—World Health Organization DPR/80. 1, version 2, September 1980.



be identified and assisted in the organisation of community-oriented disability prevention and rehabilitation. Where this family and the community have been closely involved, a village or a panchayat should be selected for a preliminary survey of the disabled within their area. This survey could be undertaken with the assistance of the trained community volunteers for identifying needs and the physical and psychological evaluation to be made by a rehabilitation team consisting of a physician or rehabilitation nurse and a psychologist or social worker specially trained for this purpose. Cases requiring medical management should be referred to an expert in physical medicine for appropriate treatment, including occupational therapy and vocational training. The remaining handicapped persons should be assessed with respect to their abilities and should then be given vocational counselling and training, following which they should be employed in community enterprises to earn a living and contribute to the socio-economic developing of the community. Leadership for such enterprises should be mobilised from within the community. Where this is weak, then expertise should be provided from rehabilitation institutions. During the preliminary phases, or the development of activities based on planning, the community may need guidance from educational (private or governmental) institutions. Careful planning, project formulation for the establishment of facilities for production and assessment of economic viability and bankability should receive due consideration before assistance is sought from financial institutions or the government itself. In this context, community-based cooperative ventures are ideal, and marketable commodities to meet local consumer needs should be the priority items for production by the disabled. Community-based private initiatives should, however, receive the support of the government. The responsibility for planning and organising these activities should be vested in a committee constituted by the community, with the active participation of the disabled beneficiaries.

### *Training*

Training is an important component of the rehabilitation programme. The disabled themselves need training, often over a long period of time, and this can be given with the assistance of members in the family of the community specially trained for this purpose. The training of the trainers will need institutional facilities at the central and intermediate levels. This training should be community-based and subject-oriented.

Often the disabled need medical attention for other health problems. A disabled person may be suffering from malnutrition, from anaemia or from circulatory or respiratory disorders requiring medical attention. There may be a need for surgical intervention for improving physical performance. Such cases should be identified and referred to medical institutions for management of these diseases before being taken up for vocational training and social rehabilitation.





The health workers at the peripheral level of health care need to have a general knowledge of prevention of disability and to acquire the skills needed to follow up and guide the disabled in their rehabilitation in both the family and community environment, and to provide medical care. The skill required need not be of professional standard; one of the peripheral workers selected for a supervisory and follow up role should be trained in basic disability prevention and rehabilitation. A training programme specially developed for this purpose and organised at the district level would be most useful.

The facilities at district level should be comprehensive in nature. Hence experts are required: the services of a physical medicine expert, a physio-therapist, an occupational therapist, a vocational counsellor, a social worker and a psychologist should be available at the district hospital. The ideal would be to organise a comprehensive department of physical medicine and rehabilitation, which would be entrusted with the responsibility of organising and supervising rehabilitation services in at least one primary health centre for the entire population served by this health unit.

Training facilities in physical medicine and in the rehabilitation of personnel for different categories should be available in the state medical colleges. To begin with, the department of physical medicine in the leading medical college in the state should be upgraded for the purpose of training all categories of personnel required for disability prevention and rehabilitation services, including research and the dissemination of information. This department should evolve patterns of services, undertake evaluation, regularly provide information to the state on disability patterns, based on surveillance and monitoring, and disseminate information to the profession and public on methods of prevention and rehabilitation.

### *Research*

Priority in research should be assigned to epidemiological studies aimed at disability prevention and at minimising the impact of handicaps on the physical, emotional and social performance of individuals. The second priority should be operational research as the knowledge available needs to be disseminated and utilised. In the developing countries, work on an appropriate technology should be promoted with special reference to the cultural and social needs of the disabled in the matter of orthotic and prosthetic appliances. Furthermore, encouragement should be given to local artisans for the fabrication of items using locally available materials. This approach promotes personalised service and consumer satisfaction.

### INFORMATION SYSTEM

An information system should be established through newsletters and journals for the benefit of the disabled, the rehabilitation personnel and the



scientists. The exchange of information promotes research and the development of rehabilitation services. In addition, periodic meetings and conferences should be organised, where the disabled, the rehabilitation workers and the scientists could get together, exchange experiences and discuss activities. Such meetings would promote national and regional collaboration.

The statement on the next page summarises the phased development of community-oriented disability prevention and rehabilitation services. Phases I, II and III show the sequence of developing a community-oriented disability prevention and rehabilitation programme. Where an infrastructure already exists, where the community is motivated and where the health services are delivering some form of rehabilitation services this sequence could be reversed.

Governmental resources are required for supplementing the community resources. Promptness in payment and curtailment of procedures for qualifying for tax funds would enhance the effectiveness of programmes supported by tax funds. A system of incentives to the community organisations would pay visible dividends. Central and state financial participation should be made available for the organisation of diagnostic and related services, vocational counselling, training, education and the preparation of training material. Medical care, including hospitalisation charges, transport, including services for the guide, the supply of orthotic/prosthetic appliances and initial equipment for gainful employment should be provided to the disabled. The establishment of business premises and workshops and purchase of initial stocks should also qualify for assistance from tax funds.

## RESOURCES

A study of the economics of preventive and rehabilitative services indicates that once a catalytic process is initiated with external or extra-budgetary resources, the community's contribution and participation are often guaranteed; community resources in terms of labour, material and cost will be readily forthcoming. An effort to explain the cost-benefit aspects to the family and the community leaders would attract more and more contributions to, and their involvement in, the organisation of rehabilitative activities. Other untapped resources are industries, banks, insurance companies and social, cultural and religious organisations. For a continuous replenishment or inflow of resources, it is important to ensure accountability and credibility, which are expected by the donors.

## CONCLUSION

Developing countries have many disabled persons who are dependent on the family and the community. A concerted effort through education and training could considerably lessen their economic dependence and contribute



## POLICY AND ORGANISATION FOR THE REHABILITATION OF THE DISABLED

<i>Activity</i>	<i>Level/Location of Operation</i>	<i>Remarks</i>
<i>Phase I—Community Based</i>	Disabled, family, community, community leaders	Creating community awareness
Identification and quantification of the problem of disabled	Surveys—local, sample, State/national	About 10 per cent are disabled—physical, visual, communication, emotional/psychological
Training of the disabled family members and community	Village/block	Primary health centre to be provided with training facilities
<i>Phase II—Population Based</i>		
Comprehensive referral rehabilitation services	District multisectoral committee	District hospital to provide comprehensive training and rehabilitation services
Training & demonstration centre	(a) Primary health centre serving a population of 100,000-150,000 (b) District headquarters—comprehensive rehabilitation centre, team approach in rehabilitation	Decentralised administration Under the auspices of voluntary agencies
<i>Phase III—State/Central (Policy)</i>		
Legislation	State Rehabilitation Committee, Central Rehabilitation Council	
Coordination	Rehabilitation Council—Centre Rehabilitation Committee—States	
Evaluation	Sub-committee	
Education and training	Department of Physical Medicine and Rehabilitation Department of Social Welfare—vocational training	Medical College
Research in appropriate technology	Institute of Rehabilitation Institute of Bio-engineering	
Resources	Community, Tax Funds—State and Central International and non-governmental agencies	
Collaboration	State, Central International Technical Cooperation amongst Developing countries	
Exchange of information	Technical Professional	Newsletter Journal



towards their participation in the social development of the community. With a national policy for rehabilitation of the disabled it should be possible to develop: (a) a programme involving education and training of the disabled, leading to their active partnership in the socio-economic advancement of the community in the developing countries, and (b) an administrative arrangement involving the participation of the communities.



## Rehabilitation of the Disabled\*

V. Ramalingaswami

THE WORLD Health Organisation estimates that approximately 10 per cent of the world's population suffers from physical, or sensorial, or mental impairment requiring special assistance. There are no reliable estimates of the nature and magnitude of disabilities in India, but it is generally believed that there are no less than 50 million persons with disability. These include the physically handicapped, the blind and visually handicapped, the deaf and the mute, and the mentally retarded and mentally ill persons. It is believed that approximately a million disabled persons are added each year to the existing numbers. Perhaps in no other sector of Indian life is the gap between what is needed and what is being provided greater; between what modern science can do and what it is actually doing. So little that is known is being applied. The situation is even more disturbing when one realises that within India itself in recent years spectacular progress has been made in the field of development of appropriate technological aids for the disabled and the disabilities both in their numbers and in their diversity are likely to increase in the future with the expansion of industry, transportation and agricultural operations, increased survival of premature infants due to better neonatal care and increasing life expectancy due to progressive reduction in mortality rates. There are about 30 institutions in India rendering rehabilitation services for the disabled: most of them are located in urban areas. The bulk of India's disability problems lies in the rural hinterland. Even if we doubled, tripled, or quadrupled, the number of such centres, the problem by its very magnitude will remain largely unresolved. We need to develop for the bulk of the afflicted persons an alternative approach to institutional management, although in severe cases of disability institutional care will become necessary. We cannot hope to solve our rehabilitation problems by 'zerox-copying' technologies developed in the West. They are inappropriate and too expensive. We need an innovative effort to develop new indigenous technologies suitable to our conditions and accessible to our people and affordable by them. To the extent it is possible

\*Based on the remarks made by me at the Symposium "Rehabilitation of the Disabled" held under the auspices of the Indian Federation of United Nations Association in June, 1981.



we must endeavour to integrate rehabilitation services with community health services.

### WHY NOT PREVENT WHAT IS PREVENTABLE?

Much of human disability is preventable and this constitutes the silver-lining to the dark clouds. A number of causative factors are involved in producing a variety of human disabilities. In our country poverty with associated malnutrition and poor environmental sanitation constitutes an important back-drop to the disability problem. With the eradication of small-pox through the preventive approach, the tragedy of blindness and disfigurement in early childhood has now disappeared from the face of our planet. Polio-myelitis, a major cause of physical disability in our country, can be prevented by the use of the vaccine at a cost of about 50 paise per person. Tuberculosis and leprosy, both leading to serious disabilities, can be prevented by appropriate chemotherapy and chemo-prophylaxis. Indeed for disabilities caused by infectious diseases, vaccination offers a feasible and effective preventive approach to disability.

Of the estimated nine million blind persons in the country, in a majority it can either be cured or prevented or arrested from further progression.

The vast problem of protein energy malnutrition in young growing children affecting the growth and development of the brain in severe cases of such malnutrition must be mentioned. If there is impaired learning ability on the part of such children, the magnitude of the problem can only be visualised. This problem is, of course, entirely preventable. There are indications that even if the resources of the country do not permit total prevention, it is possible to improve the learning ability of malnourished children by improved environmental stimulation and environmental diversity.

Insofar as accidents in industry, in traffic, transportation and agricultural operations are concerned, there is so much that can be done by mounting safety campaigns to prevent such accidents.

I can go on like this but suffice it to say that there is so much that can be done by way of prevention of human disabilities.

### HUMAN DISABILITY SERVICES

Once a disability has occurred, it must be detected early, its nature and extent must be assessed, early rehabilitation measures instituted, and the affected person is enabled to be integrated into society. The social integration of disabled persons and their participation in community activities are the main goals of the rehabilitation services. More than the disability itself it is the interaction of the disabled person with his environment that is of crucial importance. Removal of a feeling of inadequacy and inferiority, restoration of confidence and a spirit of independence are the most



important aims of rehabilitation. I think at the present time it is the family in our country that bears the brunt of the disability problem. Government and voluntary institutions play a relatively minor role at the present time. Educational and vocational training, occupational therapy and physiotherapy, provision of prosthetic and orthotic aids, of visual and auditory aids, of speech therapy, are some of the rehabilitation technologies that can be offered.

Experience has taught us that blind uncritical importation of designs developed in western countries into the eastern countryside may prove to be totally inappropriate. Our life styles, our functional needs, our climatic conditions, our barefoot walking, our squatting on the ground, all these require an innovative approach to the design of aids for the disabled in our country. Our scientists have designed simple, sturdy, durable and inexpensive appliances for our people. Experience within our country has shown how our traditional craftsmen can produce aids with their traditional technology which is appropriate in every sense of the term. The illiterate artisan limb maker can, in partnership with an enlightened surgeon, produce aids for the disabled made from indigenous materials at low cost. In Jaipur, Professor Sethi can fit a limb in 45 minutes.

Technology is only a partial answer to the problem. It is the awakening of the society that is of crucial significance. The rural poor are the least served of all the disabled persons, they are unaware of even the meagre facilities available in the country. The facilities, such as they are, are located in the urban areas. There is a climate of deprivation coupled with social ostracism that ultimately leads so many of the disabled to a life of beggary and servitude.

The tragedy of it all is that so much can be done through organised social action. One can only hope that rehabilitation of the disabled will not be just a sporadic effort to fill the days of the International Year of the Disabled, but will be a source of *continuing concern*.



# Disability in America: Paradoxes and Public Policy

Arie Halachmi

ON JUNE 22, 1981 the U.S. Supreme Court refused to trim a new right that could give handicapped children more free public education than other youngsters. The justices let stand a ruling that struck down Pennsylvania's 180 day annual limit on special programmes for physically and mentally handicapped children. Ten days later, the American television, radio and printed media were telling the story of eleven disabled persons that were climbing the 14,410 foot high Mount Rainier. The attempt of state officials to limit the commitment of the state—in economic terms—on the one hand and the public interest in the progress of the seven blind climbers, the two deaf, the climber with the epilepsy, and the one who was climbing with an artificial leg characterises the ambivalence of public attitudes towards the handicapped. This ambivalence may be the cause for some of the paradoxes in American public policy relative to various disabilities.

The purpose of this paper is to examine the selected factors that seem to bear directly on public policy making relative to the disabled in America. Specifically the paper looks at four paradoxes in this area, namely, the paradox of symbolic politics—assigning high ceremonial value of such policies without corresponding effort to provide adequate resources for their implementation; the paradox that a change in public attitudes results in a reduction of public help at the time when there is increased demand for such help; the paradox of providing help not on the basis of need but rather as a function of the interest, the resources and the ability to get organised of other than the disabled themselves. Finally the paper looks at the paradox that results when short term considerations prevail and interfere with the attempt to introduce a change that is necessary to deal with the problems of the disabled in the long, if not in the short run.

The paper concludes that public policy relative to disabled individuals may have more than a marginal and temporary effect, only if it would result from a change in basic values and norms. Such a change is a precondition for progress in this area since the public policy on disability is first of all a socio-economic policy and as such it must correspond to other social or economic policies.

It is asserted that even though this conclusion is based on limited observations and a particular situation in one country or one state, it may be





relevant and applicable to public policy making in other places. For even when and where public policy making has different characteristics, inconsistencies or paradoxes that interfere with the ability to deal with disabled people are possible.

### DISABILITY IN PERSPECTIVE : THREE VIEWS

Several writers relate the growing interest in the disabled person during the late 60s and in the 70s, in the United States, to the general interest in civil rights.<sup>1</sup>

Gerben DeJong says:

The civil rights movement of the 1960 has had an impact far beyond the racial minorities it sought to benefit. The movement made other disadvantaged groups aware of rights and of how their rights were being denied... The concern for both civil rights and benefits rights has spilled over to other vulnerable groups. In the area of mental health, patients have, in some instances, acquired the right to refuse treatment and to expect quality care. In the area of child welfare, children have acquired new procedural rights that are slowly replacing the best-interest-of-the-child rule as the legal standard for adjudicating abuse and delinquency cases. Moreover, children are receiving rights to treatment and education under special education statutes.<sup>2</sup>

From a historical perspective, public policy in the United States reflects three distinct social attitudes. First are the older views which consider handicapped persons as being incompetent to take care of their own needs or incapable of full participation in life's activities.<sup>3</sup> Decisions as to what should be done have become increasingly determined in terms of 'what is in the best interests of the larger society'. For example, when the mentally retarded were perceived as a threat to the larger society and the problem was dealt with by excluding them from society—they were sent away from metropolitan centres to isolated institutions. In the cases of institutionalisation and special class placement, there was certainly the belief that this was in the best interest of the mentally retarded individuals; however, there was also some consideration given to protecting society in these actions.<sup>4</sup>

<sup>1</sup>Seymour B. Sarason and John Doris, *Educational Handicap, Public Policy and Social History*, N.Y., Free Press 1979, p. 351.

<sup>2</sup>Gerben DeJong, "Independent Living: From Social Movement to Analytic Paradigm", *Arch. Phys. Med. Rehabil.* vol. 60 (Oct. 1979), p. 438.

<sup>3</sup>*Selected State and Federal Laws Affecting Employment and Certain Rights of People with Disabilities*, The President's Committee on Employment of the Handicapped, Washington, D.C. 1980, p. 1.

<sup>4</sup>Donald L. MacMillan, *Mental Retardation in School and Society*, Boston, Little Brown, 1977, p. 9.



Second is the view that handicapped people are capable of limited participation in some of life's activities. The corollary of this perspective is a limited definition of public and private responsibility to handicapped people.<sup>5</sup> This view underlines what Thomas Anderson and others<sup>6</sup> label as the medical model (as different from the present helping process model in rehabilitation). According to the medical model, the individual is expected to play the sick role as he is seeking help. Depending on the nature and severity of the illness the sick person is exempted from 'normal' social activities and responsibilities. Also, he is exempted from any responsibility for the illness. Hence, the individual is not accountable for his condition and is not expected to become better by sheer will. In return, the individual is expected to define the state of being sick as aberrant and undesirable, and to do everything possible to facilitate recovery. Also, the sick person is obligated to seek technically competent help and to cooperate with the physician in getting well.

While Anderson points out how the medical model may influence the attitudes of the rehabilitation professional towards the disabled individual,<sup>7</sup> Gerben DeJong examines the influence of this model on the handicapped person. He notes that the disabled person, as a result of the sick role, begins to accept not only his/her condition but also his/her own very personhood as 'aberrant' and undesirable. Moreover, the handicapped begins to accept the dependency prescribed under the sick role as normative for the duration of the disability. Thus, the sick role removes from the disabled person the obligation to take charge of his/her own affairs.<sup>8</sup> In other words, the underlying attitude that the handicapped is capable only of limited participation becomes a self fulfilling prophecy. This, in turn, justifies limited efforts of rehabilitation and without involving the individual in any decision making about them. In practice this approach justifies the concept of the sheltered workshop even though some of the individuals who are trained for these workshops can be trained for more elaborate and sophisticated jobs.<sup>9</sup>

The third view of handicapped people is that they are capable of full participation in some or all of life's activities, and that a democratic society has a responsibility to establish and maintain an environment supportive of such participation.<sup>10</sup> In a way this view implies that handicap is a matter of degree. This view emphasises the similarities between the disabled person and other people that is overlooked when the primary identification of the

<sup>5</sup>Selected States and Federal Laws, *op. cit.*, p.1.

<sup>6</sup>DeJong, *op. cit.*, p. 440.

<sup>7</sup>Thomas P. Anderson, "An Alternative Frame of Reference For Rehabilitation: The Helping Process Versus the Medical Model" in Robert P. Marinelli and Arthur E. Dell Orto (eds.), *The Psychological and Social Impact of Physical Disability*, N.Y., Springer Publishing Co., 1977, p. 17.

<sup>8</sup>DeJong, *op. cit.*, p. 441.

<sup>9</sup>Leslie D. Park, "Barriers to Normality for Handicapped Adults in the United States" in Marinelli and Dell Orto (eds.), *op. cit.*, p. 29.

<sup>10</sup>Selected State and Federal Laws, *op. cit.*, p. 1.



individual becomes his disability.<sup>11</sup> It underlies the independent living<sup>12</sup> and the normalisation/mainstreaming movements<sup>13</sup> and is well expressed in two pieces of legislation. One is section 504 of the Rehabilitation Act of 1973 that states:

No otherwise qualified handicapped individual in the United States shall solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance or under any program or activity conducted by any executive agency or by the United States postal service.

The other is Public Law 94-142 that was passed in November 1975. PL 94-142 was enacted to assure that all handicapped children have available a free appropriate public education which emphasises special education and related services to meet their unique needs to assure that the rights of the handicapped children and their parents or guardians are protected; to assist states and localities to provide for the education of all handicapped children, and to assess and assure the effectiveness of efforts to educate the handicapped children.

#### THE PARADOX OF ASSIGNING HIGH (SYMBOLIC) VALUE BUT A LOW LEVEL OF FUNDING

It is possible to identify an historical development from the very limited view of the individual as incapable of participation in life's activities to the wide perspective of the handicapped person as a full member of society. However, in this process, the emergence of the more progressive view did not eliminate or erase the other view. As a matter of fact, each view came on top of the previous ones without eliminating their influence. A case in point is the 1972 attempt to amend the Vocational Rehabilitation Act to provide independent living services to those individuals "for whom a vocational goal is not possible or feasible". The Bill was twice vetoed by the President on the ground that it "would divert the (vocational rehabilitation) program from its basic vocational objectives toward more ill-defined medical and welfare goals". DeJong observes that, eventually, the President did sign what became known as the 1973 Rehabilitation Act, albeit with the independent living provisions deleted.<sup>14</sup>

In a similar fashion the limited responsibility of public and private organisations to accommodate the handicapped is expressed in many local and

<sup>11</sup>Shirley Cohen, *Special People*, Englewood Cliffs, N.J., Prentice-Hall 1977, p. 9.

<sup>12</sup>DeJong, *op. cit.*, pp. 435f.

<sup>13</sup>Park, *op. cit.*, p. 25.

<sup>14</sup>DeJong, *op. cit.*, p. 451.



state statutes dealing with architectural accessibility and barrier removal. In this case, even when the law establishes such requirements, there are enough provisions and grounds for a waiver of the requirement or an unclear specification of the enforcing agency and few legal remedies to assure compliance with the law.<sup>15</sup>

The gap between the spirit of the law and the effectiveness of the mechanism by which it is implemented is one paradox of public policy-making relative to the handicapped in America. In the case of section 504 that provides no provision for waiver of the requirement for accessibility there were a series of litigations regarding how this law may be enforced.<sup>16</sup> In a similar fashion Erwin Hargrove notes that in the case of PL 94-142 "federal and state regulations tell school districts *what* to do but not *how* to do it, and certainly not how to do it effectively."<sup>17</sup> According to one position paper, this gap between the spirit of the law and its possible impact on the welfare of the disabled is likely to grow further as a result of the proposed legislation to leave the implementation of programmes to the states. In the words of this white paper:

The overall thrust of these changes is to abolish over ninety separately authorized Federal programs and to remove Federal agencies from program control. Activities carried out under those standards, regulations, budget allocations, technical assistance, and audit authority, with few exceptions, would be located at the state level. This shift of responsibilities will leave an enormous and immediate vacuum in policy, budget allocation and choice of grantees.<sup>18</sup>

This possible paradox is one of giving high symbolic value to official declarations about noble intentions to enhance the status of the handicapped with a simultaneous reduction in the amount of actual efforts to deal with specific issues or problems, relative to the welfare of the handicapped. This possible paradox is illustrated, if not amplified, by the President's proclamation of 1981 as the International Year of Disabled Persons in the U.S. while proposing at the same time a policy that reduces the amount of resources available for different programmes for the handicapped.<sup>19</sup>

<sup>15</sup>For comparisons of the laws of different states see *Selected State and Federal Laws, op. cit.*, pp. 14f.

<sup>16</sup>*Ibid.*, p. 13.

<sup>17</sup>Erwin C. Hargrove, "The Spirit of the Law", *American Education*, 17 (1) January/ Feb. 1981, p. 10.

<sup>18</sup>Jule M. Sugarman, *Human Services in the 1980's: A White Paper for Citizens and Government Officials* (Draft), U.S. Council for the International Year of Disabled Persons, May 15, 1981, p. 1.

<sup>19</sup>The possible impact of the proposed changes in federal policy is presented in Sugarman's White Paper, *op cit.*



What are the reasons for this possible paradox and is it the only one influencing public policy in America? In the following pages I will try to show that this seeming paradox is the result of an historic process and the institutional characteristics of the policy making process.

#### THE PARADOX OF CHANGING PUBLIC ATTITUDES UNDER ECONOMIC STRESS

The discrepancy between the President's declaration on February 6, 1981 that "All of us stand to gain when those who are disabled share in America's opportunities"<sup>20</sup> and his efforts to consolidate or abolish over ninety federally funded programmes may be explained by reference to the context of the policy making process. On its face, the President's policy is not a reaction or retraction of federal policies in this area. Rather, Reagan's policy is aimed at the division of labour as far as the responsibilities of each level of government are concerned, *i.e.*, federal intervention *vs.* states' rights. The predicted adverse effect on the welfare of the disabled in each state is going to be, therefore, a function of each state's level of dependency on federal resources in each category of activities or services for the handicapped. That is, the final impact on the welfare of the disabled is going to be influenced by the extent that his own state's developed local services as a result of local initiative or because of the availability of federal funds or requirements for such services.

The involvement of the federal government in the provision of services and protecting the right of the disabled has several roots. With the risk of over-simplifying some and leaving out others, these can generally be grouped into the following categories:

1. Pressures from parents, groups for public support and maintenance of different programmes for disabled children.<sup>21</sup>
2. Emergence of national associations of citizens with different disabilities, like the Kidney Foundation or the American Coalition of Citizens with Disabilities, to lobby policy makers in Washington.
3. Specialisation within the helping professions, *e. g.*, education or medicine that resulted in pressure for special programmes, research grants, representation on policy making bodies and licensing.
4. Concentration of large numbers of poor in certain states or urban areas.
5. Inability of states or local authorities to meet the needs of the poor and disabled residents.

<sup>20</sup>Ronald Reagan, "International Year of Disabled Persons: A Proclamation", Federal Interagency Committee for the International Year of Disabled Persons, Washington, D.C., Feb. 1981, p. 111.



6. Failures of state and local authorities to supervise the quality of services rendered to disabled people, *e.g.*, in the case of private (and even state) institutions for the mentally insane.<sup>22</sup>
7. Influences of the civil right movement on the role of the federal government in prevention of discrimination or violation of civil rights, *e.g.*, in the case of housing, work or education.
8. Availability of census data about the magnitude of the problems which crossed state lines like the revelation by the department of education that an estimated 8 million children in the U.S. have mental, physical, emotional, or learning handicaps, and that only about half of them received education programmes appropriate for their needs, if at all.<sup>23</sup>
9. The greater fiscal capacity of the federal government in mobilising the necessary resources for developing services, training of professionals, funding of research and demonstration projects, and in providing legal and economic aid to disabled children and adults.
10. Growth and development of the federal bureaucracy dealing with the implementation of public laws in this area. *e.g.*, the department of education in the case of P.L. 94-142.
11. Growing tendency of the media and the performing arts to carry stories of human interest about the misery of some disabled persons and success stories of others.

As a consequence of the growing interest and involvement of policy makers at the national level in the public policy relative to the disabled, federal agencies, on their own initiative, or at the direction of Congress, placed many more controls on the provision of state and local services. At the same time federal funds became a much larger share of the total human services expenditure.<sup>24</sup> Many times these federal funds were used to by-pass state and local authorities to sponsor programmes by private or non-profit organisations.

The availability of federal funds (or matching funds) and the involvement of the federal agencies in the different programmes at the state and local level influenced state and local policies in two ways. First is the influence on the state or local government list of priorities which was changed artificially to include programmes that would result in a larger share of federal support for services and particularly in those cases when this meant creation of more jobs for local residents in general. Second is the influence on the organisational structure of state and local agencies that were reorganised to reflect the organisation of federal agencies with whom each authority had to deal. As

<sup>22</sup>The grim findings about the prevailing conditions in such institutions inspired several books and movies.

<sup>23</sup>*Unanswered Questions on Educating Handicapped Children in Local Public Schools.* A Report to Congress by the Comptroller General of the United States, p. 1.

<sup>24</sup>Sugarman, *op. cit.*, p. 2.



in the previous case, such reorganisations resulted from the existence of policies that were exogenous to the state or the local authority as political and socio-economic systems. Thus, the need to adopt to the external environment resulted in a compromise or rejection of an administrative structure that would have been more responsive to the system's inner needs for stability and support.

The reaction of the public to these two influences was expressed in the growing opposition to the deep involvement of the federal government in various activities on the state and local level, the growing taxation and the claims that federal spending is constantly feeding the inflation. Thus, while the American voters did not express a direct and clear position on where they stand in regard to the public policy about the disabled, as far as values and symbols are concerned, they did express their resentment of the way this policy was being implemented. The seeming paradox in President Reagan's position while proclaiming the International Year of the Disabled in the US and his budget proposal is therefore not a real paradox. In both cases the President seems to follow the popular wish, even though this popular wish may have been internally inconsistent.

For our purpose here, it seems that the lesson of this recent development in the public policy, relative to the disabled, is that disability cannot be dealt with independently of economic considerations. This, in turn, suggests still another paradox that seems to hold true for other aspects of the welfare state. It looks as if the public as an entity is not willing to make economic or political sacrifices even when these are necessary to produce subsequent economic and political gains. Specifically, *the paradox is that under relatively 'good' economic conditions the public is willing to help out and accept the disabled because of humanitarian values and recognition of their civil rights. Yet, as times get hard for everybody—including the disabled—this willingness goes down even though this change of attitude deprives this public of some of its own human resources.* This paradox is even greater, considering the fact that the public is more willing to make the economic sacrifice to accommodate a disabled child than the disabled adult who may be able to contribute to society—if not to the economy or the polity—more readily. I must emphasise here that the point I am trying to make is not that the disabled children enjoy too many services but rather that not enough is being done in order to enhance the welfare of the disabled adults.

There may be different reasons for the drop in the availability and quality of programmes for the disabled adults. Yet, in this paper, I want to concentrate only on one of them, namely, the characteristics of the so called 'public support' for such programmes. As will be suggested in the following discussion, these characteristics may influence not only the public efforts to deal with various age groups of the disabled individuals but the possible difference between the efforts for dealing with each disability regardless of age.





### THE PARADOX OF HELPING THE 'INTERESTING' DISABILITIES

Public law 94-142 requires that a free appropriate public education be available for all handicapped children, age 3 to 18, by September 1978, and age 3 to 21 by September 1980. Yet, what is the ultimate impact of this law on the welfare of handicapped individuals? The US department of education reports that 80 per cent of the handicapped individuals are, within one year of leaving school, at best unemployed, or dependent on welfare, under total care or both.<sup>25</sup> By the same token Shirley Cohen reports the case of an autistic child who was lucky enough to start getting this education even before he was 3 years old. Cohen concludes that "had (the parents) waited a year and a half or two years for their sons' education to begin" as prescribed in P.L. 94-142, "they might have lost him to his impenetrable world."<sup>26</sup> These two examples suggest that by setting age limits for eligibility the law, at best, reduces the effective impact of the programmes to enhance the status of the disabled. At worse, this law that is heralded by many as the best law (in the books) as far as the welfare of the disabled is concerned, may be responsible for vast waste of resources and for substituting real efforts for symbolic politics. To be sure, in the latter example of the individual who needs to get a service before he is 3 years old—if future programmes are to be effective in helping him to be a full member of society—the age barrier may be the cause for the futility of future efforts. Yet, even though, the child is past the point when an effective change can be influenced as he reaches the age of 3, the law mandates and legitimatises the use of scarce resources until he is 18 or 21 years of age. In the earlier example, leaving the individual on his own, regardless of whether he is able to be independent, because he has reached the age of 18 or 21 years, suggests that the previous investment in his education since he was 3 years old (as specified by P.L. 94-142) is being lost.

The use of chronological age, which is an artificial criterion, to determine eligibility for a service rather than by a criterion which is relevant to the conditions under consideration raises several questions. One of them has to do with the rationality of the policy, when the law, by which it is expressed, has built-in barriers for achieving its ultimate goal. Why is it that instead of reference to need, eligibility for service is determined by age in the case of developmental disability or the prospect of returning to work in the case of disability that results from renal disease? The answer seems to be in the nature of the policy making process as a political process. Namely, that like policy making relative to any other aspect of life, the interest group (or coalition) that is better organised ends up with a bigger share of the

<sup>25</sup>Maurice McInerney and OYV C. Karm, "Federal Legislation and the Integration of Special Education and Vocational Rehabilitation", *Mental Retardation*, 19(1) Feb. 1981, p. 21.

<sup>26</sup>Cohen, *op. cit.*, p. 115.





available resources. Hence, while public policy on the handicapped is meant to deal with the needs of the individual disabled, it caters first to the needs, wishes or priorities of those that see it through the policy making process.

A quick comparison of two of the policies relative to renal disease patients and to individuals with mobility problems in the state of Tennessee may help to illustrate this point.

Several state agencies are involved in the implementation of federal and state regulations concerning individuals with mobility impairments. However there is no specific programme for direct and continuous assistance to the mobility handicapped.

A recent study on government policies affecting mobility impaired adults in the state of Tennessee concluded that "in fact, the bulk of state policy exists as a result of federal mandates brought about through pressure from national lobbying groups or possibly advocacy groups organised in other states."<sup>27</sup> It is not surprising, therefore, that each department in the state of Tennessee was left to form its own policies and interpretations of section 504 of the 1973 Rehabilitation Act.<sup>28</sup> The status of public policy, relative to the mobility impaired, is well illustrated by the fact that the governor's liaison office for the employment of the handicapped did not have possession of the policy statements of the various state agencies.<sup>29</sup>

Unlike the case of the mobility impaired, a state law established a special programme to deal with renal disease patients within the Tennessee department of public health.<sup>30</sup> The department, according to this law, is directed:

- (a) to assist people suffering from chronic renal disease who require life-saving care and treatment, but who are unable to pay for such services on a continuing basis;
- (b) to pay for treatment of renal disease patients and to help equip specialised dialysis centres for their care;
- (c) to assist in development and expansion of programme for the care of people suffering from chronic renal disease;
- (d) to insure that approved patients receive quality medical care and that the patients' physical well-being is given top priority.<sup>31</sup>

In comparison, individuals with mobility impairments cannot get more

<sup>27</sup>Lora Lavin, James U. Lowe and Karen Tyler, "Government Policies Affecting Mobility Impaired Adults of Tennessee and their Impact", unpublished seminar paper, Master Program in Public Administration, Tennessee State University, July 1981, p. 25.

<sup>28</sup>*Ibid.*, p. 22.

<sup>29</sup>*Ibid.*

<sup>30</sup>Data for this illustration is based on Richard Bise, Sherryle Midgett, Jean Moss, Harold Reeves and Doye Rowland, "State Policies Affecting Persons Handicapped by Renal Disease in Tennessee".

<sup>31</sup>*Tennessee Code Annotated*, Chapter 47.



than a short term assistance under a rehabilitation programme following the development of the disability (e.g., after an accident or illness). It was observed that in most cases the functional/service relationship between the individual with the latter disability and state agencies cease to exist after the initial rehabilitation stage that ends when the individual is fitted with an artificial limb and is helped to get a new job. Specifically, any other problems, e. g., inability to pay rent, or transportation expenses, are being dealt with by welfare agencies if the individual qualifies to be a welfare recipient or if he qualifies for medicare and medicaid in the case of medical expenses. This state of affairs is illustrated in the case of the state's efforts to elevate problems that result from architectural barriers. Even when the state amended its Public Building Accessibility Act.<sup>32</sup> to comply with Federal regulations under section 504 of the 1973 Rehabilitation Act, it delegated the responsibility for monitoring compliance to the 'responsible authorities'. However, these 'authorities' were given wide discretion to grant exceptions from the requirements of the Act.<sup>33</sup>

To understand the difference in the amount of effort and resources that are committed by the state of Tennessee in order to deal with the disabled individuals in these two categories one must look at the sources of support for the programmes in each category.

In the case of the mobility impaired it was observed that "only one public advocacy group was identified in Tennessee which specifically addresses the problems in independent living for the mobility impaired, a Memphis chapter of the Paralyzed Veterans of America."<sup>34</sup> Hence the study concludes that in the case of the mobility impaired "we find that there is no well organised coalition of outside groups at the state level speaking for the needs of the disabled."<sup>35</sup> As a contextual variable the lack of such support, by other than the disabled themselves, may explain the difference in the state policies relative to the mobility impaired and the renal disease patients.

In the case of the renal disease, Tennessee has three well organised chapters of the National Kidney Foundation. These chapters mobilise local support that influences state legislators. The pattern of operation on the state level is no different from the mode of operation used by the National Kidney Foundation at the federal level in 1972 to mobilise support for a federal programme to assist individuals in defraying the cost of treatment.

The foundation itself is enjoying a lot of support from groups and individuals other than kidney patients or their immediate family because

<sup>32</sup>*Laws of Tennessee Relating to the Handicapped* (1980 Edition). Issued by the Tennessee State Planning Office, pp. 227-229.

<sup>33</sup>*Ibid.*, Section 53-2548, p. 228.

<sup>34</sup>Lavin, Lowe, and Tyler, *op. cit.*, p. 12.

<sup>35</sup>*Ibid.*, p. 25.



among others, its objectives include:

- mobilisation of support for kidney research and training for such research;
- fostering the continuing education of health care professionals; and
- monitoring of health policy development.

Specifically, the foundation enjoys the support of physicians, academic institutions with medical and/or bio-engineering research programmes, training facilities, manufacture of dialysis machines and paraphernalia, and employees of dialysis centres. In Tennessee this support can be easily mobilised to exercise the needed pressure on state and local policy makers through such bodies like:

The Council on Clinical Dialysis and Transplantation,  
 The Council of Nephrology Nurses and Technicians,  
 The Council of Nephrology Social Workers,  
 The Council on Renal Nutrition, and  
 The Council on Urology.

In addition to direct influence on state legislators for appropriation of resources to support the kidney programme, *e.g.*, the transportation of patients to dialysis centres through the use of state funds, the Kidney Foundation and related interests are represented in the Renal Disease Advisory Committee.<sup>36</sup> The committee is established by law to make recommendations to the Commissioners of Public Health on various policy matters. The composition of the committee appears in Table 1.

TABLE 1 RENAL DISEASE ADVISORY COMMITTEE

<i>Descriptive Category</i>	<i>Number of Members</i>
Hospitals with established dialysis center	two physicians two hospital administrators
Medical schools with established dialysis centers	one physician
Volunteer agencies interested in kidney diseases	one member of the national kidney foundation
Local public health agency	one director of a public health department
Physicians licensed to practice medicine in all branches	two physicians
The general public	two members of the general public

<sup>36</sup>The Renal Disease Advisory Committee is appointed by the Commissioner of Public Health under Section 53-4702 (Tennessee Code Annotated).



From the Table it is possible to see that a variety of organisations and agencies with vested interest in strong kidney programmes are in a position to influence, if not to actually determine the nature and scope of the kidney programme in the state. This direct participation in the policy making process is in addition to other activities of the Kidney Foundation to influence other participants in the public policy making process which it monitors continuously.

What is the reason for such a difference among the state policies in regard to various disabilities? The answer seems to be in line with the old observation that education, monetary resources and social status have much to do with the ability and effectiveness of participation in the political process. The ability to get organised determines eventually the political effectiveness of each group of disabled people. However, this ability is greatly influenced by the involvement of physicians and other professionals in on going research and care in each category of disability. The extent to which interest groups other than the patients themselves can influence state (and even federal) policy making is illustrated in the following case:

In 1980, the three affiliates of the Tennessee foundation asked the department of public health to request supplemental funding to cover both transportation costs of patients and administrative costs. Until that time, appropriated dollars had only been used for 'hands-on' treatment. There was no money available to pay for administrative expenses. The department did not consider this to be a high priority budget item and did not support the request.

The Kidney Foundation contacted Representative Joe Kent, a state legislator from Memphis, to solicit support for their request. Representative Kent met with Lewis Donelson, then commissioner of the department of finance and administration, concerning the supplemental funds request. An amendment was subsequently added to the appropriations Bill incorporating the requested subsidy. This additional funding created an inconsistency in that, during the same year, actual services were cut back, yet the programme was receiving additional money for patient transportation and administrative costs.

In the case of individuals with mobility problems, discontinuity in the functional/service in the connection between the individual and the physician (or any other professional) after the initial rehabilitation period is both a cause for and a result of the state policy. This discontinuity in turn 'deprives' the handicapped in this category of disability of the organisational benefits that result from an on going (and therefore deeper) involvement of physicians and other professionals in the public policy making process as they lobby for additional services and resources for their own training and research. Thus, even though there are more people with mobility impairments than kidney problems in the state of Tennessee, their relative influence on policy making is lower. This, in my opinion, is due primarily to their failure to



'attract' the attention of those who are more likely to get organised and participate in policy making, *i.e.*, the highly specialised professionals.

This observation seems to be in line with a previous observation in the area of mental retardation. Donald MacMillan points out that classes for trainable mentally retarded (TMR) were established before classes for educable mentally retarded (EMR—mildly retarded) despite the fact that the latter group is far larger in number. He points out that parent groups in the case of TMRs tend to be more of a middle class and upper class background while parents of EMRs tend to come from lower social class. MacMillan concludes that "the parents of the mildly retarded were either less aware of their children's special learning needs or less adept politically to get a response from educators to their special needs."<sup>37</sup>

#### THE PARADOX OF SHORT TERM CONSIDERATIONS AND LONG TERM SOLUTIONS

On July 20, 1981 *U.S. News and World Report* featured a story about the on going evaluative efforts in Washington towards a possible rewriting of the regulation under section 504 of the 1973 Rehabilitation Act. The article "Equal Access It Seemed Like a Good Idea" starts as follows:

Washington is taking a long, second look at an obscure law that would *cost* bus and subway systems billions of dollars to obey, yet *benefit* only a relative handful of people.<sup>38</sup>

The idea, according to the officials that were interviewed for this feature, is to permit local authorities less costly means for obeying the 1973 law.<sup>39</sup> Pointing out that this effort is part of an overall effort of the Reagan administration to economise, reduce spending and intervention of the federal government in state, local and private activities. This story is another illustration of the fact that socio-economic policies cannot be dealt with separately. For that matter, I see any public policy relative to disabled persons as a socio-economic policy with broad implications even though it may appear, or be introduced, as a welfare; health; labour; education; transportation; housing or civil rights policy in the most limited sense.

A case in point is the observation by Sarason and Doris that the roots of the opposition to mainstreaming (which has to do with public policy relating to disabled children) "was long contained in the political-administration-social structure of departments and schools of education in our universities"<sup>40</sup> which has to do with the sociology (or sociology of knowledge

<sup>37</sup>MacMillan, *op. cit.*, p. 24. On the importance of the influence of parents organization on policymaking see also Sarason and Doris, *op. cit.*, p. 357.

<sup>38</sup>Jeammye Thornton, "Equal Access—It Seemed Like A Good Idea", *U.S. News and World Report*, July 20, 1981, p. 45 emphasis added.

<sup>39</sup>*Ibid.*

<sup>40</sup>Sarason and Doris, *op. cit.* p., 36.



in our society). It is hard to conclude whether the relative low status of special education as a field of study, research or training was the cause of past policies in regard to disabled children or the result of the low status of the special education teacher "who was expected to be a good custodian rather than any effective educator"<sup>41</sup> which defines a social or an educational policy. Yet, as implied by several writers,<sup>42</sup> a possible obstacle for implementing public policy relative to disabled individuals at the present has to do with the inability of various professionals to coordinate and put their act together because of other unrelated policies and professional traditions.

The effort to enhance the welfare of the disabled individual cannot be expected to have more than marginal effects as long as there is no fundamental change in societal attitudes and consequent changes in all of our social policies. True, even a spatial improvement in the welfare of the disabled individuals is important. However, without the conscious effort to change the basic mores of society, such improvements may turn out to be temporary and yield to the pressure of other short term considerations like benefit cost ratios, government involvement, public responsibility, etc. To improve public policy relative to disabled people we must recognise and deal with the possible *paradox that as long as these and other short term considerations prevail, it is impossible to influence the long term change which, in turn, may resolve the possible discrepancy among systemic, societal, individual and social needs.*

Testimony to the existence of this paradox can be found in: (a) The demands to allow each sub-system to operate, relatively independent, within its legal boundaries commensurate with its fiscal ability. This is demonstrated by the unhappiness of state and local authorities with federal requirements. Or, (b) the demands to enable each individual to become a contributing member of society (as illustrated in the claims of the independent learning movement).<sup>43</sup> Or, (c) in the demand not to compromise the welfare of the individual for the sake of a sub-system or society as expressed by a 'simple' or a 'partial' benefit-cost analysis in the case of urban public transportation or architecture barriers in rural areas. Or, (d) the demand to cater to the needs of groups not only as a function of their ability to get organised and to participate in the political process but also as a function of their *inability* to do so. As pointed out earlier this inability might have influence; Tennessee's policies relative to individuals with mobility problems because there were no organisations of parents, entrepreneurs, scientists, physicians or other professionals to support and lobby for programme (*i.e.*, for allocation of public resources) to meet their needs.

□

<sup>41</sup>Sarason and Doris, *op. cit.*, p. 360.

<sup>42</sup>Hargrove, *op. cit.*, pp. 10-11, McInerney and Karan, *op. cit.*, pp. 21-22

<sup>43</sup>DeJong, *op. cit.*, p. 437.

## Let's not Handicap the Handicapped

Nana Chudasama

**U**NTIL RECENTLY, the thought that society had a responsibility towards those who struggle under physical impairment was not generally accepted. But now society is slowly awakening to the rights of the handicapped.

The old attitude that the handicapped were to be shut away in institutions or cared for privately by their families, but the public was not to be embarrassed by being exposed to their plight, has changed.

Not only is there an awareness of the problems faced by the physically handicapped persons, but there is also a growing awareness that society is obligated to cater to the needs of such citizens. At the same time, there is a new consciousness among the handicapped individuals of their right to function as integral members of our society.

It is estimated that nearly 450 million people in the world are handicapped. Out of these, the figure in India is surmised as forty million.

Who can be termed a handicapped person?—anyone whose condition limits substantially one or more major life activity. The disabled, like the able-bodied people, come in all shapes and sizes. More often than not, they are psychologically injured, since they feel dependent not only for moral support, but for their very mobility.

They, however, do not want pity or handouts. They want a fair deal. They want to be accepted as capable where they are capable; they do not want their handicap to be made an issue. All they ask is that some adjustments should be made to qualify them for employment.

The official IYDP emblem represents two people holding hands in solidarity and support of each other in a position of equality. The principal objectives spelt out by the UN foresee all national and international efforts to provide disabled persons with proper assistance, training, care and guidance, to make available opportunities for suitable work, and most importantly, promoting effective measures for prevention of disability. Educating and informing the public of the rights of the disabled persons to participate and contribute in the economic and social life, is another important objective.





To attain these objectives, the following steps are suggested:

First and foremost there should be adequate consultation and coordination among agencies. A national association should be formed to control and coordinate all activities.

It is essential to formulate a national policy at the highest level for both medium and long term plans.

There is a need for a broad programme of public education and widespread dissemination of information on this subject.

There should be an interchange of information, advice, research and public education to bridge the communication gap. An information channel must be made available for experiences, research, case studies and other relevant data of the personnel through different media.

### BARRIERS TO BE REMOVED

As long as we continue to 'handicap' disabled people, we continue to handicap ourselves. We must, therefore, seek to break various barriers which wall them in. The blatant ones: architectural and transportation obstacles. The unnecessary ones: unrelated medical criteria used in job requirements; The subtle ones: attitudinal barriers which are the hardest to topple. We should remember that unless we integrate the handicapped into every aspect of society, we will permanently keep justice disabled.

Many developed countries have enacted legislation to further the rights of the handicapped such as construction to be designed without architectural barriers to the handicapped; prohibiting various forms of discrimination against the handicapped like business houses to take affirmative action to employ qualified handicapped persons; prohibiting arbitrary barriers to the full participation in society of any group of handicapped individuals.

Voluntary agencies as well as government and semi-government bodies should assist in the administration of organisations for the handicapped. Besides appropriating and collecting funds, their other important functions should be to identify the handicapped, train them for gainful employment, find them a niche in the commercial and industrial houses, provide them with transport facilities and also cater to their recreational needs.

An outstanding example of a methodical approach to help the disabled could be a programme leased on the following framework:

1. Registration for employment or helping the handicapped.
2. Assistance in medical check up and assistance in surgery.
3. Centralised assessment centre for employment or training.
4. Vocational guidance/counselling service.
5. Assistance for purchase of artificial limbs, appliances, tricycles, etc.





6. Dissemination of information about scholarships, concessions, loans, etc., available for disabled.
7. Removal of architectural barriers at public places.
8. Library containing literature in the field of rehabilitation for the disabled.
9. Mobility acceleration programmes recreation/centre, outwa1d bounds activities.
10. Publication of quarterly bulletins of employed disabled persons in the cities.
11. Sports festivals for disabled persons.
12. Workshop for rehabilitation programme for disabled.
13. Arts and crafts exhibition by handicapped.

In this International Year of the Disabled persons, the attention of the public has been focused on their plight. The momentum generated should not be allowed to die down. It's the depth of feeling of each one of us for the cause of the handicapped, which, in the final analysis, will bring out the success or failure of the organisation and administration for the handicapped.

## **Administration of Social Welfare Programmes for the Physically Handicapped in India**

**N.R. Inamdar  
and  
Nalini Paranjpe**

**T**HE PHYSICALLY handicapped are as much the citizens of the country as the able bodied persons. It is not as if the physically handicapped are unable to do any work and the able bodied can perform all sorts of work. On the other hand, a defect in one part of the body may stimulate the activities of the other organs and senses.

The modern age has not only conceded to the handicapped individual the right to education but also the right to earn a living and become a contributing member of the community. Having recognised this right, it would follow that modern welfare services should provide for special educational and training facilities, employment opportunities and even recreational facilities to the handicapped. It is important to emphasise this because the traditional attitude to charity has persisted through the years and this is the single most hurdle to the provision of the right type of services for the handicapped.

Welfare services for the handicapped may be divided into two categories: (1) services promoting the maximum degree of economic independence of a handicapped individual, and (2) services providing a minimum comfort of life. These services should also promote complete integration of the handicapped individuals into society. There is often a tendency to grant the handicapped an exclusive status. Any attempt on the part of the handicapped to secure preferential treatment at the expense of other normal members of the society is likely to injure their cause. The guiding principle for the handicapped and the organisations working for them should, therefore, be to secure such facilities as would bring about the total integration of the handicapped individual into the society.

Rehabilitation has been defined as the act of restoring forfeited rights and privileges. Generally speaking the term, 'physically handicapped', includes all persons who have either completely lost the use or can make only a restricted use of one or more of their limbs, *i.e.*, total or partial functional disablement.



The physically handicapped are classified as<sup>1</sup>:

1. those lacking in one or more physical senses, *i.e.*, blindness or deafness or in combination;
2. those suffering from movement difficulties, *i.e.*, orthopaedic, malnutrities and cardiacs; and
3. lepers, epileptics, rachitics and dumb persons.

Although the Indian Parliament's 23rd Estimates Committee (1957-58) had strongly recommended a survey of the handicapped persons,<sup>2</sup> their total number in India has never been correctly estimated. Reasons are several, such as defective enumeration, lack of definition, and the desire of the afflicted persons to avoid publicity to their handicaps. However, this lacuna would be remedied with the publishing of the 1981 decennial census in which a question has been included on the handicapping conditions. This may yield reliable information for rationalising the present welfare services and for the future planning of social welfare services for the handicapped.

India has a large population of different categories of the physically handicapped, and even though statistics are not available, the dimensions of the problem are of sufficient magnitude to be a cause for concern. The irony is that much of these handicaps are preventable, since they are caused by inadequate health care and other social services in rural areas and urban slums, resulting in poor health and nutrition, illiteracy, etc.

Before independence, services for the disabled were developed and implemented by voluntary organisations and the government followed a policy bordering on *laissez-faire*. After independence, however, the Government of India assumed increasing responsibility in providing rehabilitation services, acknowledging that the handicapped must cease to be a burden on the society and must be included in the productive activities of the country like its normal citizens. The First Plan marked a turning point in the history of rehabilitation—a change from charity to rehabilitation. In the Second Plan emphasis was placed on the education and employment of the physically handicapped. During this period, the Government of India envisaged the schemes for awarding scholarships to the disabled students and establishing special employment exchanges for the disabled. In the Third Plan, stress was laid on the development of training facilities geared to employment and on increasing the scope of employment opportunities for the handicapped. The Plan also thought in terms of

<sup>1</sup>*First Five Year Plan: Social Services*, New Delhi, Government of India, Planning Commission, 1954, pp. 632-33.

<sup>2</sup>*Estimates Committee, 23rd Report, 1957-58*, New Delhi, Lok Sabha Secretariat, 1958, para 99, p. 31.



coordination of the activities undertaken by the various Central and State Governments and voluntary agencies. The Fifth Plan reiterated the Third Plan's emphasis on employment of the handicapped.

Rehabilitation programmes have thus a dual interest: on the one hand, they are concerned with the well-being of the handicapped individual and the seek to restore him to the maximum vocational functioning and social participation, *i.e.*, self-reliance of which he is capable. On the other hand, they have a broad national purpose in helping to conserve and improve the human resources needed for national reconstruction and development, *i.e.*, to integrate the handicapped into the main stream of the society.

### ORGANISATION

The Central Social Welfare Board (CSWB) established in August, 1953 functioned under the Ministry of Education and enjoyed an autonomous position.<sup>3</sup> In April 1969 it was registered as a company under the Indian Companies Act, 1956.<sup>4</sup> The main objective of the Board is to develop welfare programmes in general and programmes for the physically handicapped in particular, through a network of voluntary social welfare organisations.<sup>5</sup> At the State level, the State Social Welfare Advisory Boards were set up to organise programmes for the physically handicapped; and at the district level, Project Implementation Committees were set up to take up welfare programmes in areas where voluntary organisations did not exist.

Although the CSWB has been granted functional autonomy for facilitating the implementation of welfare programmes, it continues to function, in practice, like any other government department beset with redtapism, and an obsessive preoccupation with accountability to Parliament. Consequently, costs and regularisation of finances become major considerations rather than the accruing of social benefits.

The Union Education Ministry set up the National Advisory Council for the Education of the Handicapped in 1955 to advise the Government of India on various problems concerning the education, training, employment and recreational amenities for the physically handicapped.<sup>6</sup> It coordinates the rehabilitation activities of the voluntary non-governmental agencies. Similar advisory councils have been formed at the State level.

The All India Institute for Physical Medicine and Rehabilitation (AIIPMR) offers consultative services and assistance to other institutions for the initiation and development of basic rehabilitation services. It coordinates the rehabilitation programmes of certain hospitals and cooperates

<sup>3</sup>The Central Social Welfare Board, *Annual Report 1977-78*, New Delhi, CSWB, p. 1.

<sup>4</sup>*Ibid.*, p. 1.

<sup>5</sup>*Ibid.*, p. 1.

<sup>6</sup>United Nations, *Study on Legislative and Administrative Aspects of Rehabilitation of the Disabled in Selected Countries*, New York, 1964, para 216, p. 59.

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with the special employment exchanges by training special placement counsellors and evaluating the vocational potentialities of disabled persons.

### FINANCING

The directorates of social welfare in the various states allocate special budgetary grants to the voluntary agencies for the education and rehabilitation of the handicapped. The Union Education Ministry sanctions *ad hoc* grants for the education of the handicapped and establishment of special educational institutions. The Union Labour Ministry also extends budgetary grants for the employment of the disabled.

The CSWB under its general grants-in-aid programme extends financial assistance in the form of one year grants, plan period grants, building grants and grants for the purchase of mobile vans to voluntary organisations engaged in welfare activities for the physically handicapped.<sup>7</sup> Grants-in-aid to the extent of ninety per cent of the estimated cost for taking up projects or programmes for the education and training of the physically handicapped are sanctioned to voluntary organisations.<sup>8</sup>

TABLE 1 GRANTS-IN-AID SANCTIONED TO VOLUNTARY ORGANISATIONS DURING THE PERIOD 1975-81

	<i>Grants in aid (Rs. Lakhs)</i>	<i>Number of Voluntary Organisations</i>
1975-76	65	90
1976-77	90.82	203
1977-78	80.00	112
1978-79	95.56	120
1979-80	90.03	110
1980-81	100.00 (1 crore)	120

SOURCE: *Social Welfare Reports, 1975-76 to 1980-81.*

The voluntary organisations engaged in welfare work for the handicapped face financial problems due to several reasons, such as, inadequacy in grants-in-aid, delays in getting the sanctioned aid, inability of raising matching grants through donations, etc.<sup>9</sup> Mismanagement of funds and corruption also mar their financial administration. With the exception of some voluntary agencies, most of the other welfare organisations do not have adequate and suitable accommodation. Some of the

<sup>7</sup>*The Central Social Welfare Board, Annual Report 1977-78, op. cit., p. 9.*

<sup>8</sup>*Social Welfare Report 1977-78, New Delhi, Government of India, Ministry of Social Welfare, 1978.*

<sup>9</sup>*Study of the Working of the Aided Voluntary Agencies in Social Welfare Programmes, New Delhi, Government of India, Planning Commission, Programme Evaluation Organisation, 1978, para 8, p. xiv.*



residential institutions utilise their buildings not only for holding classes but also as residence.<sup>10</sup> Since the needy voluntary agency is required to raise fifty per cent of the total expenditure on construction or purchase of a building through donations they cannot approach the CSWB for building grants.

The voluntary agencies, suffering from a chronic shortage of funds, are not able to employ suitably trained staff having an aptitude for this kind of work at reasonable salaries. For example, the average salary (pay with allowances) for the teaching, medical, supervisory, ministerial, paramedical, and extension workers is Rs. 204.80.<sup>11</sup> Shortage of funds also leads to inadequate furniture, clothes, books, crafts and equipment.

To a great extent, the growth of voluntary agencies has been nurtured by the policies adopted by the government. However, a large number of these institutions do not have a local base and their existence itself may be endangered if there is any diminution in the flow of grants from the Central Government, the Central and State Social Welfare Boards or the State Governments. Because of the dependence of the voluntary agencies on government aid for their survival, these agencies have adopted a policy of inducting influential public men as office-bearers in order to secure administrative and financial aids from the government and cooperation from the public for raising matching contribution through donations.<sup>12</sup> Consequently, the voluntary organs have become mere extensions of national or State governmental organisations functioning through the local representatives of political parties or government officials. Such a practice would be detrimental to the interests of the handicapped since the public men as office bearers would not have the requisite time or adequate dedication for the welfare work they have volunteered for. It could be suggested that the managing committee of a voluntary agency should be constituted through election to broad base it and also to include enthusiastic and dedicated members with an aptitude for social work. Representation should be given in the executive body to the handicapped persons themselves. Voluntary organisations should be decentralised as a majority of them are working in urban areas. The nature and scope of these agencies should be streamlined and responsibility should be fixed on them. Attempts should be made to evaluate the performance of the voluntary agencies from the point of relative costs and efficiency in achieving their objectives. Malpractices and corruption have to be dealt with summarily by the immediate stopping of grants.

The Renuka Ray Committee (1959) and the Bulsara Committee (1964) had stressed that the CSWB should effect coordination among voluntary

<sup>10</sup>*Study of the Working of the Aided Voluntary Agencies in Social Welfare Programmes, op. cit.*, para 3, p. xiii.

<sup>11</sup>*Ibid.*, Table No. A. 5.4, p. 109.

<sup>12</sup>*Ibid.*, para 1, p. xiii.



agencies to avoid overlapping and wastage of resources in the working of the organisations. With the increasing participation of the governments, there is an urgent need for effective coordination through the establishment of coordination committees.<sup>13</sup>

## SERVICES

The existing rehabilitation programme in India extends to a number of hospitals, specialised institutions and training centres. While the starting of services at the grassroot level is the responsibility of the States, the Central Government had allotted Rs. 3.65 crores during the Fifth Plan for developing a national institute for each major category of the physically handicapped, such as the blind, the deaf and dumb, the orthopaedically handicapped, etc., to engage in research and undertake the training of personnel.<sup>14</sup>

### *Medical Care*

Rehabilitation services, including diagnosis, restorative and surgical treatment, physical and occupational therapy, are provided at the AIIPMR, exclusively for the orthopaedically handicapped; J.J. Hospital, Bombay; Children's Orthopaedic Hospital, Bombay; Irwin Hospital, New Delhi, etc.<sup>15</sup> The Employees' State Insurance Corporation has also introduced rehabilitation departments in its hospitals.

The Institute for the Physically Handicapped, a registered society functioning under the Ministry of Social Welfare, since 1975, supplements the services provided by the AIIPMR.<sup>16</sup>

In India, little progress has been made in the manufacture of prosthetic appliances. Although the Artificial Limbs Centre set up in 1972 at Poona, the Orthopaedic Factory of the Jerbai Wadia Hospital, Bombay, the Institute for the Physically Handicapped, etc., produce appliances and aids for the orthopaedically handicapped, they are beyond the reach of the poor. The Department of Social Welfare, Government of India, does reimburse 50 to 100 per cent of the costs of such appliances depending upon the income of the beneficiary<sup>17</sup> but due to ignorance about this scheme not many of the handicapped benefit from it.

There is acute shortage of personnel specialising in the different aspects of rehabilitation and therefore the need to train qualified professional staff has become an important need of the rehabilitation programmes.

<sup>13</sup>*Study of the Working of the Aided Voluntary Agencies in Social Welfare Programme*, op. cit., para 7, p. xiii.

<sup>14</sup>*Social Welfare Report, 1973-74 and 1978-79*, op. cit., pp. 38, 44 respectively.

<sup>15</sup>*United Nations, Study on Legislative and Administrative Aspects of Rehabilitation of the Disabled in Selected Countries*, op. cit., para 219, p. 59.

<sup>16</sup>*Social Welfare Report, 1980-81* op. cit., pp. 41-42.

<sup>17</sup>*Welfare of the Disabled Persons*, Bombay, Government of Maharashtra, p. 43.





The AIIPMR and other hospitals and institutions conduct intensive programmes and seminars for the training of the professional personnel, social workers and vocational counsellors for physical, social and vocational rehabilitation. But the services of the trained personnel are limited to a section of the urban society only.

### *Education and Vocational Training*

*The Blind:* The National Institute for the Visually Handicapped (previously the National Centre for the Blind) was established in 1979, at Dehra Dun.<sup>18</sup> It runs two secondary schools for the blind and partially blind children. A training centre for the adult blind, a sheltered workshop for the employment of the blind, a workshop for the manufacture of Braille appliances, the Central Braille Press for publishing Braille text books, the National Braille Library, and four teacher training centres at Bombay, New Delhi, Calcutta and Madras.

*The Deaf and the Deaf-Mute:* The Training Centre for the Adult Deaf at Hyderabad established in 1962 imparts training to the adult deaf (age group 16-25 years) in various engineering and non-engineering trades. The school for the partially deaf children at Hyderabad tries to integrate the partially deaf children with the normal children.<sup>19</sup> During the period 1962 to 1980-81, 578 trainees passed out of this centre.<sup>20</sup>

*The Orthopaedically Handicapped:* The National Institute for the Orthopaedically Handicapped was established in Calcutta during 1979-80.<sup>21</sup> The standard of education and training is believed to be not very high in this institution.<sup>22</sup> This may be due to the limited teacher training facilities.

There is need to establish an extensive network of educational and training institutions since the existing institutions have limited capacity. The Education Commission (1964-66) had recommended that educational facilities for about ten per cent of the total number of handicapped children should be provided.<sup>23</sup> To increase the educational opportunities for the handicapped children the Commission recommended integrated education. Consequent to this recommendation the Central Government has provided 100 per cent assistance to State Governments for admitting handicapped children in ordinary schools to promote their integration in society and to reduce costs. In 1979-80, 81 schools joined this scheme and about 1,881 handicapped children benefited from it.<sup>24</sup>

<sup>18</sup>*Social Welfare Report, 1980-81, op. cit., p. 32.*

<sup>19</sup>*Ibid., pp. 39-40.*

<sup>20</sup>*Ibid.*

<sup>21</sup>*Ibid., p. 39.*

<sup>22</sup>A.R. Wadia (ed.), *History and Philosophy of Social Work in India*, Bombay, Allied Publishers Private Limited, 1961, p. 331.

<sup>23</sup>*Report of the Education Commission 1964-66*, New Delhi, Government of India. Ministry of Education, 1966, Part I, Para 6.46, p. 124.

<sup>24</sup>*Social Welfare Report, 1980-81, op. cit., p. 44.*





The Education Commission had also recommended the coordination of efforts of the different agencies working in the field of education and training, such as the Ministry of Education at the State and Central levels, the CSWB, the State Social Welfare Boards, voluntary organisations, etc., to avoid wastage of resources.<sup>25</sup>

In order to enable the physically handicapped children belonging to the economically weaker sections of society to benefit from the educational facilities, the Union Ministry of Social Welfare has been granting scholarships, since 1955, for general education and professional or technical or vocational training from the 9th class onwards.<sup>26</sup> However, the beneficiaries do not receive the scholarships promptly. Ignorance on the part of the concerned persons results in malpractices. In this respect the educational institutions can serve as effective communicators. The Administrative Reforms Commission undertook a study of the procedures for the award of scholarships and recommended measures to expedite the process of selection and payment.<sup>27</sup>

TABLE 2 SCHOLARSHIPS GRANTED TO THE PHYSICALLY HANDICAPPED DURING THE PERIOD 1976-1981

<i>Year</i>	<i>No. of Scholarships and Stipends Awarded</i>
1976-77	2,744
1977-78	4,412
1978-79	7,095
1979-80	8,900
1980-81	9,500 (proposed)

SOURCE: *Social Welfare Reports for the years 1976-77 to 1980-81.*

The special educational institutions and the scholarships scheme aim at helping the physically handicapped children to become useful, independent citizens. However, the emphasis is on giving the handicapped children a liberal or general education.<sup>28</sup> These children after the completion of their education are not adapted to the employment market. Hence the difficulty in finding jobs for them increases as the employment opportunities in general get restricted. An attempt has to be made to adapt training to those sectors of employment market that are not too over crowded and which appeal to the employers.

### *Job Placement*

The Government of India has set up 18 special employment exchanges

<sup>25</sup>*Report of the Education Commission 1964-66., op. cit., para 6.49, p. 125.*

<sup>26</sup>*Social Welfare Report, 1976-79 and 1980-81, op. cit., p. 44, 44 respectively.*

<sup>27</sup>*Ibid., 1973-74, p. 39.*

<sup>28</sup>*The Central Social Welfare Board—A Study of the Programmes (1953-1969), New Delhi, The CSWB, Research Evaluation and Statistics Division, p. 46.*



and appointed special officers in ordinary employment exchanges for the placement of qualified and skilled handicapped persons in suitable jobs.<sup>29</sup>

The Government of India has envisaged a policy reserving 3 per cent vacancies for the physically handicapped in groups 'C' and 'D' posts in the Central Government as well as in comparable posts in the public sector undertakings. The State Governments have also reserved posts for the handicapped.<sup>30</sup>

In the placement of the handicapped persons the special employment exchanges have not been very effective for a variety of reasons. Except for general or liberal education which has a limited scope for employment, the handicapped have restricted opportunities for engineering or other technical education but for the reserved seats. Although the Central and State Governments have reserved posts and relaxed age limits, such provisions, in practice, are not implemented.<sup>31</sup> Hence the special employment exchanges can play only a limited role.<sup>32</sup>

The Inter Ministry Coordination Committee for the Rehabilitation of the Handicapped was set up in 1980-81 to review whether suitable posts have been identified and reserved for the employment of the physically handicapped in the Government Services.<sup>33</sup>

TABLE 3 JOB PLACEMENTS EFFECTED BY THE SPECIAL EMPLOYMENT EXCHANGES SINCE INCEPTION TO 1978

Year	No. of Placements
Since inception till 30-9-74	12,540
1975	1,244
1976	1,810
1977	1,508
1978 (Jan-September)	1,109
Total:	18,211

SOURCE: *Social Welfare Reports for the years 1973-74—1980-81.*

To promote employment of the physically handicapped, substantial financial assistance is given to voluntary organisations for setting up integrated workshops employing various categories of the physically handicapped. However, the employment offered by such workshops is limited. For example, the sheltered workshop for employing trained blind persons offers employment to about 40 persons annually.

<sup>29</sup>*Social Welfare Report, 1979-80, op. cit., p. 43.*

<sup>30</sup>*Ibid., 1978-79, p. 43.*

<sup>31</sup>India, *Lok Sabha Debates, Series 6, Session 6, 27 November 1978, col. 122-23, 205-206.*

<sup>32</sup>*Social Welfare Report, 1980-81, op. cit., p. 47.*

<sup>33</sup>*The Central Social Welfare Board—A Study of the Programmes (1953-1969), op. cit., p. 155.*



The above mentioned are basic services provided by law (unlike in India) in countries like the USA, UK, USSR, etc. However, in some countries like the USA, pre-vocational orientation programmes are given. In others, as in USSR, home instruction for vocational training is provided. Elsewhere in UK, France and now in India greater emphasis is laid on the integration of the handicapped children into normal schools. In some countries, education is compulsory for handicapped children.<sup>34</sup>

In most of the countries a close cooperation is sought between voluntary agencies and regional and local administrations.

Among such voluntary organisations mention must be made of the trade union organisations in the USSR which take an active part in the administration of the rehabilitation services, with particular emphasis on its social and vocational aspects.<sup>35</sup>

TABLE 4 GRANTS-IN-AID SANCTIONED BY THE CSWB FOR THE WELFARE OF THE HANDICAPPED DURING 1953-69

<i>Period</i>	<i>Grants Sanctioned According to Field of Service (Rs. in Lakhs)</i>	<i>Per cent Distribution of the Amount Sanctioned to Field of Service</i>
I Plan	9.30	12.32
II Plan	29.20	9.92
III Plan	23.55	9.56
1966-69	11.85	9.69

SOURCE: *The Central Social Welfare Board—A Study of the Programmes (1953-1969)*, New Delhi, Central Social Welfare Board—Research, Evaluation and Statistics Division.

The percentage of grants-in-aid sanctioned during various plan periods (Table 4) indicates that the welfare of the handicapped does not rank very high in the system of priorities of the CSWB. It should be given the same priority as in case of welfare of children and women.

#### CONCLUDING OBSERVATIONS

A study of the welfare services provided to the physically handicapped persons reveals that financial constraint is the major factor. Allocations for social welfare services for the handicapped persons still continue to be regarded as 'consumption expenditure' with the frequent connotation that they represent a drain on the economy. Although the Third Plan stresses 'balanced' social and economic development and 'human investment' or investment in 'human resources' the latter is ignored in practice. The Plan also emphasises change in attitude in the welfare schemes of the handicapped,

<sup>34</sup>United Nations, *Study on Legislative and Administrative Aspects of Rehabilitation of the Disabled in Selected Countries*, op. cit., p. 162.

<sup>35</sup>*Ibid.*, p. 166.



but the attitude is still one of charity which may be adopted by the voluntary agencies. But since the country has placed before itself the ideals of a welfare state and a socialistic pattern of society, the state has to play a greater role by way of supplementing the efforts of the voluntary organisations.

The primary motives underlying the organisation of social welfare facilities for the handicapped are humanitarian rather than economic. The principle of equal opportunity and the universal right to optimal personality development are more basic to social welfare than any possible economic gains from special programmes of training, education and rehabilitation of the physically handicapped. The resources available for social welfare facilities for the handicapped will always be severely limited in a developing country where the number of activities geared to eliminating the vulnerability of the under privileged sectors of society is large. Here, cost-benefit analysis can contribute information that is helpful in reaching decisions on the best use of available resources.

Demonstration of probable economic and social benefits in the form of independence and employability as against the expenditure on the dependent handicapped for life will create a more positive attitude towards social services for them and also strengthen the current trend towards the 'normalisation' of handicaps. Since social attitudes are reflected in the behaviour of individuals, such a development would have welcome consequences for the handicapped themselves, their families, employers, etc.

No doubt, the costs of total rehabilitation of the physically handicapped are heavy. But, since the attainment of the objective would eliminate the vulnerability of the physically handicapped, planned progress in the direction towards the objective has to be realised in the foreseeable future.



## **The Need for Radical Changes in the Administrative Structure of our Services for the Disabled**

**H.J.M. Desai**

**T**HE SAN Francisco Conference leading to the establishment of the United Nations in 1945 had, in its preambular recitation, reaffirmed its "faith in fundamental human rights, in the dignity and worth of the human person, in the equal rights of men and women and of nations large, and small".

The disabled should also fully enjoy all fundamental human rights. Their human dignity must at all times be respected.

The United Nations has repeatedly—and in the clearest terms—shown its deep concern for disability prevention, treatment and rehabilitation of the disabled.

In 1969, the General Assembly included in its objectives the establishment and improvement of social security and insurance schemes for all persons who, because of disability, are temporarily or permanently unable to earn a living. It also called for the protection of the rights and the ensuring of the welfare of the disabled and the provision of protection for the physically and mentally disadvantaged.

Again, in the Declaration on Social Progress and Development, the General Assembly urged the institution of appropriate measures for the rehabilitation of mentally or physically disabled persons, especially children and youth, so as to enable them, to the fullest possible extent, to be useful members of society. It further emphasised that these measures should include the provision of treatment and technical appliances, education, vocational and social guidance, training and selective placement and other assistance required and the creation of social conditions in which the handicapped are not discriminated against because of their disability.

### **DECLARATION ON THE RIGHTS OF DISABLED PERSONS**

On December 9, 1975, the General Assembly adopted the Declaration on the Rights of Disabled Persons. The Declaration has taken the utmost care for the protection of disabled persons and for grant to them of the rights and privileges as well as the same respect and human dignity



so far assigned to people who do not suffer from such handicaps.

In the report of the Secretary General, United Nations, on the International Programme for the Rehabilitation of the Physically Handicapped submitted to the eighth session of the Social Commission, he has emphasised:

- (a) that every handicapped person should be entitled to receive such protection, assistance and opportunity for rehabilitation as may be necessary and appropriate to enable him to share, in as great a measure as possible, the privileges and responsibilities of full life in the society of which he is a member,
- (b) that every state should, in principle, recognise its responsibility for the taking of all possible measures for the prevention of handicap and for the provision of appropriate care, social assistance, education and rehabilitation for its handicapped citizens.

The United Nations General Assembly has adopted several excellent and comprehensive declarations such as the 1971 Declaration on the Rights of the Mentally Retarded Persons and the 1975 Declaration on the Rights of Disabled Persons. The specialised agencies of the United Nations have also passed several important resolutions on various aspects of the problem of the disabled.

Have we made an earnest and sincere attempt to implement all such declarations? Have these declarations been even discussed in our Parliament and in our Legislative Assemblies and have we earnestly endeavoured to evolve national policies, plans and programmes for the rehabilitation of the disabled based on these declarations? Have we ever reviewed—in Parliament and in our Legislative Assemblies—the progress made in the implementation of these declarations in the adoption of which we had ourselves a major share? The disabled rightly feel that—unfortunately for them—they remain mere pious resolutions on paper! Even now, if we sincerely work for the implementation of these declarations and resolutions, a tremendous lot of progress can be made in a short time. It is never too late to make a beginning. But deep involvement at the level of our parliamentarians, legislators and administrators is a must.

#### INTERNATIONAL YEAR OF DISABLED PERSONS

Against the background of deep international concern for the disabled referred to in the preceding paragraphs, when the representative of the Libyan Arab Jamahiriya, moved the General Assembly of the United Nations in the matter on December 16, 1976, it promptly proclaimed 1981 as the International Year of Disabled Persons. India is one of the 23 member states on the advisory committee appointed for IYDP, 1981. Hence our



responsibility for ensuring implementation of the objectives of IYDP, is great.

The theme of the year is 'Full Participation and Equality'. The logo represents two people holding hands in solidarity and support of each other in a position of equality.

Dr. Kurt Waldheim, Secretary General, United Nations, has emphasised that the General Assembly, by proclaiming 1981 as the International Year of Disabled Persons "aimed at focussing attention on the enjoyment by disabled persons of rights and opportunities in order to ensure their full participation and integration into society. The effort to find solutions to the problem of disabled persons should be an integral part of national development strategies".

### THE PROBLEMS OF THE DISABLED

The United Nations has estimated that at least one person out of ten of the population of any country is affected by some kind of disablement. On this basis, it is estimated that at least 450 million people on earth suffer from some form of physical or mental impairment.

An expert group of the United Nations has estimated that one quarter of the inhabitants of any community are directly affected by disability, through the time and resources spent by the family members and others in the community in care and in compensating the handicaps. In the light of this colossal drain on our manpower resources, is it not better to do everything possible to prevent disabilities? Experts say that it is much more economical to prevent disability than to organise and maintain rehabilitation services over a life span.

Our Prime Minister, while inaugurating the IYDP 1981, stated that India had some 60 million disabled. Thus, nearly one eighth of the total disabled population of the world lives in India. It is obvious that the problem is one of colossal magnitude—of gigantic proportions—and requires to be tackled on top priority basis and—if I may say so—on a war footing.

The Government of India report on blindness, 1944, compiled by the internationally reputed expert on blindness—the late Sir Cluthe MacKenzie—had estimated the blind population of India at 2 million. Today the government estimates the totally blind at 5 million and the economically blind—*i.e.*, those who cannot earn a living wage because of this disability, at 9 million.

Since 1947, Pakistan and since 1971 Bangladesh are separate countries. One would think that with the spread of medical and health services to the rural areas, the number of the blind should substantially decrease. What has gone wrong that the number has so very substantially gone up? Are we—at the Union and State levels—taking sufficient care and adequate action to prevent disabilities?



## OBJECTIVES OF IYDP

The five principal objectives for the Year set out in the General Assembly Resolution are as under:

1. Helping disabled persons in their physical and psychological adjustment to society;
2. Promoting all national and international efforts to provide disabled persons with proper assistance, training, care and guidance, to make available opportunities for suitable work and to ensure their full integration in society;
3. Encouraging study and research projects designed to facilitate the practical participation of disabled persons in daily life, for example, by improving their access to public buildings and transportation systems;
4. Educating and informing the public of the rights of disabled persons to participate in and contribute to various aspects of economic, social and political life;
5. Promoting effective measures for the prevention of disability and for the rehabilitation of disabled persons.

Given the genuine will and cooperation of all concerned, these objectives are not at all difficult of implementation.

## DIFFICULTIES IN INDIA

All problems in India are of a colossal magnitude. The financial resources available are meagre. There is a dearth of technically trained personnel. There is also shortage of technical aids, appliances and equipment required in the rehabilitation of the disabled. India is a sub-continent. Approximately, 80 per cent of the disabled live in the rural areas—in our 565,000 villages. The majority of the institutions for the disabled are located in towns and cities. Hardly a handful are in rural areas or work for the disabled from rural areas. The existing institutions for the disabled must be catering to the needs of barely two per cent of the disabled population in the country. The rest are left to the mercies of a cruel fate and eke out a bare existence or depend on family or public charity.

## THE DISABLED IN INDIA

Today, two-thirds of the world population live in underdeveloped countries. It would be no exaggeration to say that forty per cent of them live in absolute poverty which, in economic terms, means that they have no adequate income to get the basic necessities of life. Most of them are





denied health and education facilities.

A very vast majority of the disabled in our country belong to the low income group. Nature has denied them the precious gift of vision or a limb or a function. Should society impose on them additional handicaps? Should we deny to them medical treatment and medical rehabilitation? Should we deny to them the elementary right to education? If education is free and compulsory for normal children, why should it be denied to the blind? Because nature has inflicted on them a disability, should we also deny to them employment or equal opportunity for economic resettlement and a normal family and social life? Should we discriminate against them merely on the ground of disability? Why don't we accept them as normal members of the family and society and fully integrate them into the normal community? If we meditate for a while and search our conscience for truthful replies, we would realise that we have failed miserably in promoting the rehabilitation and welfare of the disabled.

#### PROGRESS IN INDIA SINCE INDEPENDENCE

Having said the above, I must frankly state that to my personal knowledge, tremendous all round progress has been made in the rehabilitation of the disabled after we attained independence. The Ministry of Social Welfare has made a good job of an extremely difficult and delicate task. For example, the provision made in the Sixth Plan is about 200 times as high as the one made in the First Plan. However, the number of the disabled involved is so large that whatever we do, it appears like a mere drop in the ocean!

Our Prime Minister set up a national committee for planning IYDP, 1981. Four groups on drafting legislation for the disabled, employment of the disabled, education, and grant-in-aid have been appointed. These groups have made good progress.

If the considered recommendations of these expert groups are accepted, I foresee all round progress in the rehabilitation of the disabled.

On her own signature, the Prime Minister has issued letters to all ministries requesting them to ensure that the employment quota of three per cent for the disabled in government offices must be fulfilled. If all our legislators and administrators are motivated in the same manner, progress is not difficult.

#### SERVICES DELIVERY SYSTEM FOR RURAL AREAS

In the light of what is stated in the foregoing paragraphs, it is imperative that we pay great thought to evolving a system of delivery of services so as to serve the disabled, scattered all over India. We must evolve strategies to take our services to the rural areas. It would definitely be wrong to attract the rural disabled to cities where accommodation is almost impossible to



secure, where mobility presents great difficulties for the disabled accustomed to rural life—particularly the blind—and where the cost of living is prohibitive. The rural disabled find it difficult to tear themselves away from their families and friends and from their familiar rural surroundings. Transfer causes psychological and emotional disturbances and makes it difficult for them to adjust to their disabilities. Even to take them to towns and cities for training is wrong in principle because once they have spent a few years in cities, they normally do not like or want to return to the villages. Government should, therefore, encourage the setting up of new rehabilitation centres only in rural areas.

Thought may be given to the use of the existing revenue and health machineries in the identification and referral of the disabled to appropriate training institutions.

Now that we have primary health centres, it should not be very difficult to attach a rural rehabilitation counsellor for the disabled to such primary health centres after giving him/her a short term intensive training in the rehabilitation of the disabled. The rural rehabilitation counsellors will be able to locate disabled clients, guide them and their families and refer them to appropriate institutions either for further medical treatment and care or for rehabilitation or for training and employment. They can also assist them in numerous other ways.

#### DISTRICT LOCAL AUTHORITIES

In the United Kingdom, by an Act of Parliament, the responsibility for looking after the disabled is statutorily placed on the district local authorities. Such authorities are required to refer the disabled to appropriate institutions and also to bear all the costs involved in their training and rehabilitation.

In a country of the size of India, it would be a good idea if the responsibility for medical, educational, vocational and economic rehabilitation and welfare of the disabled is statutorily placed on the district local authorities such as the zilla parishads. This would ensure that the disabled in the remotest parts of the country can get the benefit of medical treatment and rehabilitation services. The district local authorities may be empowered to impose a small levy from the proceeds of which they can meet the cost of providing rehabilitation services.

#### OUR EXISTING ORGANISATIONAL STRUCTURE

It is my humble opinion that our existing organisational structure for dealing with the problems of the disabled is not sound.

We need to take a fresh and close look both at the level of government and at the level of voluntary agencies.



At the Centre, the Ministry of Social Welfare is entrusted with the task of providing services for the disabled. I would, however, like to see here a basic change. In several national and international conferences, it has been urged that the education of the disabled should be under the Education Ministry. Disability prevention and cure is rightly for the Health Ministry. Vocational training and employment falls within the purview of the Labour Ministry. Similarly, the Agricultural and Rural Reconstruction Ministry should be entrusted the task of rehabilitation of the rural disabled. In this way the maximum possible use of the existing infrastructure and the existing machinery can be made at the minimal additional cost. The budget would also be spread over all the concerned ministries. The Ministry of Social Welfare must continue to work as the coordinating ministry for the disabled. This would ensure good progress and rapid advancement.

At the State level, the State departments of social welfare and the directorates of social welfare are entrusted with the responsibility of training and rehabilitation of the disabled. Even at the state level, the concerned departments should handle appropriate subjects pertaining to the disabled.

The directorates of social welfare are entrusted with several other subjects such as looking after juvenile delinquents, beggars, tribals, etc. Obviously, the twenty-two or so directorates in the country are not in a position to cope with the several different and difficult aspects pertaining to the training and rehabilitation of some 60 million disabled in the country.

The Government of India deserves to be congratulated on designating an officer of the status of a joint secretary in the Ministry of Social Welfare as the commissioner for rehabilitation of the disabled, but it is imperative that in the ministry are created specialist cells for each category of disability, manned by specialists in the disability so as to build up expertise at the highest level of policy formulation, planning, programming, budgeting, and evaluating the performance and progress in the rehabilitation of all categories of disabled with divergent and different problems.

#### **DIRECTORATES FOR THE REHABILITATION OF THE DISABLED**

It is also imperative that every state creates an exclusive directorate of rehabilitation of the disabled, if we are serious about the education, vocational training, employment, economic resettlement, social integration and the welfare of the disabled in the country. As constituted at present, the existing directorates of social welfare just cannot do justice to this colossal human problem.

#### **RADICAL CHANGES IN THE SET UP OF VOLUNTARY AGENCIES FOR THE DISABLED**

At the outset, I must say that voluntary agencies for the disabled have



done magnificent pioneering work despite initial difficulties. Their work is all the more praiseworthy as it has been done at a time when public awakening is just not there, when financial resources are meagre and technically trained personnel not available.

However, in the last two or three decades, tremendous advances have taken place the world over in the fields of disability prevention, treatment and cure, reducing the adverse effects of disability and in the rehabilitation of the disabled.

Our voluntary agencies are rather conservative. They still follow the traditional and conventional patterns. It is time that the modern advances are carefully studied and adopted to our local needs. Creative and innovative type of work has to be undertaken. The voluntary agencies should introduce modern concepts and advances to the great benefit of the disabled. In this task, international agencies are always willing to help and guide.

### MODERN MANAGEMENT TECHNIQUES

Management techniques and business administration have made tremendous strides in the last couple of decades. State and national level voluntary agencies for the disabled would do well to seek expert advice from consultancy services on reorganising and modernising their set-ups—particularly their facilities for vocational training, workshops and production units. It has been amply demonstrated the world over that production units manned by the disabled can work successfully on modern business lines and make full commercial profits. The disabled could be fully productive if the plant is planned on modern and scientific lines and the trades selected so as to facilitate full output and production by the disabled.

Our voluntary agencies would do well to follow modern management techniques, to recruit the right type of technically qualified staff, to train and motivate such staff, to modernise their workshops, to introduce more sophisticated trades and crafts and to secure technical expertise of the right type.

### INDIVIDUALISED AND PERSONALISED REHABILITATION

In all progressive countries, the principle that the greater the disability, the greater the responsibility of the state for the medical, vocational and economic rehabilitation and welfare of the disabled has been fully accepted.

In some countries, legislation requires that the state shall chalk out programmes for the rehabilitation and resettlement of individual disabled persons, thus ensuring personalised attention to each disabled person. Rehabilitation programmes are required to be 'tailor made' to meet the personal requirements of individual clients.



## NATIONAL POLICY AND NATIONAL PLAN FOR THE DISABLED

In the light of the various declarations adopted by the United Nations and the resolutions passed by the specialised agencies of the UN, the Union and the state governments should be responsible to provide, free of all cost, adequate facilities for the medical, educational, vocational and economic rehabilitation and welfare of the disabled, ensuring their full participation—with equality—and total integration into the normal community life.

It should be recognised that every person suffering from a disability shall have the right, and be eligible to receive, free of all cost, medical, surgical and all other kinds of treatment; the appliances and equipment the use of which may reduce the adverse effects of the disability and restore the functional abilities of the person, even to some small extent.

The inalienable right of the disabled person to work and his full participation in the community should be accepted and he should have equality of opportunity in all spheres of life.

The Parliament should adopt a policy statement fully spelling out the national policy and plan for the rehabilitation of the disabled so as to provide broad guidelines for our legislators, administrators, voluntary agencies and the entire community in the country.

It is also imperative that a high level parliamentary committee of both the Houses is appointed to periodically review and watch the implementation of the various declarations and resolutions adopted by the United Nations and its specialised agencies. This committee should also review the progress made in the implementation of the national policy and plan for promoting the rehabilitation and welfare of the disabled and issue directives to plug loopholes, give more liberal financial allocations to accelerate the pace of progress in the total rehabilitation of the disabled in the country. In particular, the progress made in all the states and the progress made in the employment and economic resettlement of the disabled should be periodically watched and the pace of their employment and resettlement be very substantially accelerated so as to arrest the growing frustration and discontent among the trained disabled.

## NON-DISCRIMINATION

In several countries, there is legislation against discrimination on the only ground of disability. It is necessary to legislate that no disabled or handicapped individual shall, solely on the grounds of his disability or handicapped, be discriminated against or be refused admission and equal treatment in any educational, training or any other institution or in social or cultural organisations, bodies or clubs. No employer shall, solely on the ground of the handicap or the disability, discriminate against the disabled



or handicapped individual and deny him employment opportunities, opportunities for promotion and advancement, or equal treatment.

### ROLE OF OUR LEGISLATORS AND ADMINISTRATORS

Our parliamentarians, our legislators and our administrators—both at the level of policy formulation and at the level of implementation—have a very major role to play in the medical, educational, vocational and economic rehabilitation and welfare of the disabled. They must realise that this is a human problem to be treated as such.

The problems of disabled should be discussed in Parliament and in the state legislative assemblies at least twice a year, statistical data of the numbers involved and the progress made be brought to their notice and solutions evolved for further promoting their rehabilitation and welfare.

Our administrators should be fully conversant with and be motivated to do their very best for this humanitarian cause. The problem has to be viewed purely from the human and humanitarian angle, where necessary by relaxing normal rules and norms. Tremendous progress could be achieved by positive and constructive attitudes and approaches of our administrators dealing with the rehabilitation of the disabled.

### FINANCIAL ALLOCATIONS

If the problem of the 60 million and odd disabled in India is to be satisfactorily solved, even in the next two or three decades, it is imperative that liberal financial allocations are made available in our five year plans, in our annual budgets of the Union and the state governments, municipal corporations and local authorities. If necessary, a special levy should be permitted so as to enable the district local authorities to raise adequate funds for tackling this gigantic problem on a human basis.

### RADICAL CHANGES IN PUBLIC ATTITUDE

If integration of the disabled into the normal community has to be achieved and is to be meaningful, it is necessary to do everything possible to bring about a radical change in public attitude to problems of the disabled. Integration in the normal community should start right from the school stage. This should best be promoted by providing for integrated education of the disabled—including the blind—in normal schools, polytechnics and all other types of institutions. Fullest possible use should be made by the disabled of all normal community resources. The disabled should be allowed to fully avail of the benefits of all normal approved Union and state government schemes and they should not be discriminated against



merely on the ground of their disability. Only then can the concept of integration make some progress.

### SCIENCE, TECHNOLOGY AND RESEARCH IN THE SERVICE OF THE DISABLED

Thanks to Jawaharlal Nehru, India is fortunate in having a number of national research laboratories.

It is necessary to do everything possible for prevention of disability by eradicating the common causes leading to disabilities. It is necessary to involve the national research laboratories in preventing and seeking solutions for the rehabilitation of the disabled. The world over, it is now realised that it is much more economical to prevent disabilities than to maintain life-long rehabilitation services for the disabled. In humanitarian terms, the gains are immeasurable.

Our leading scientists, technicians, technocrats and research workers should also be involved in developing new aids, appliances and equipment, that would facilitate the training, employment and rehabilitation of the disabled. Research has a very important role to play in the solution of their problems. The disabled themselves should be encouraged to identify problems needing research and thereafter the national and other research laboratories be entrusted to study the problems and work towards their solution. To my mind, it is imperative that we motivate and involve top ranking scientists, technicians, mechanical, electrical and electronic engineers, research workers and specialists in different disciplines to work for the disabled so as to get the benefit of their expertise and specialisation in their respective fields.

### ECONOMIC GAINS

The costs of dependency are tremendous. The loss to the economy of the country—due to idle manpower—is colossal. Modern advances have proved that rehabilitation and training can restore a very substantial majority of the disabled to near normalcy and productive work. Rehabilitation can make the disabled fully productive and contributive members of society. Those rehabilitated successfully can become tax-payers—rather than continuing to remain as tax-consumers. The disabled at work generate new purchasing power. They boost up the morale of the work force and by their own greater production, motivate labour to better efforts. Thus they contribute to the economy of the country. Besides, rehabilitation reduces—to the extent possible—unnecessary human suffering. It restores human dignity of the individual. These advantages are very positive. They cannot be evaluated in monetary terms alone. Rehabilitation adds to the sum total of human happiness. The financial investment made in the training and





rehabilitation of the disabled repays itself many times. Rehabilitation helps to integrate the disabled in the national mainstream.

I would, therefore, humbly submit that our Parliament should—at the earliest—evolve a national policy and a national plan for the rehabilitation and welfare of the disabled. It should, at the earliest, issue a national policy statement on the subject. It should pass a comprehensive legislation which will take care of the medical, educational, vocational, economic and social rehabilitation and welfare of the disabled. It should periodically review progress made by the various ministries in the rehabilitation of the disabled.

Only with such high level intervention and action will dawn a new era in which IYDP 1981 would truly be meaningful to the 60 million disabled in our country.





## **Administration for the Disabled—Policy and Organisation**

**M. Natarajan**

**T**HE DISABLED are those who, due to deficiencies in movement, vision, hearing or mental faculties are unable to offer their total participation in their individual and social functions. They will thus come under the category of the weaker sections of our community.

The constitution of India has assured equality of opportunity for all sections of the population with special assistance to the weaker sections.

The noble ideals enshrined in the constitution by our founding fathers have to be translated into effective action if the disabled population of India is to be assisted in the full participation in the mainstream of social life.

It is now accepted that roughly 10 per cent of the population in the country will come under the category of the disabled, according to an estimate by the World Health Organisation.

It is heartening to note that the global conscience of mankind has been kindled to take note of the present state of the disabled in the world, express concern and also promote action by declaring 1981 as the International Year of the Disabled Persons.

The national governments all over the world have in turn announced their awareness and concern regarding the welfare of the disabled population. It must be remembered that in India there has been increasing awareness and expressed concern since 1947, and various activities have grown up in the official as well as non-official sectors to promote the welfare of the disabled during the last three decades.

It is true that knowing the size of the problem helps one to formulate plans and targets in solving it. In a developing country like India, all problems are unimaginably huge and the resources for meeting them are unfortunately very limited. Thus action programmes on a manageable scale are always welcome at least to bring the people concerned face to face with the realities of the problem at the grassroot level which, in turn, help them to plan realistically on the basis of acquired experience and expertise.



## ORGANISATIONAL WEAKNESS

Those of us who have been committed to the cause of the disabled and have been involved in some programmes have always felt that our biggest weakness is the lack of some infrastructural organisation on a state and national level which would coordinate, stimulate, oversee and monitor activities and help them to be more productive, and avoid overlapping and wastage. Total rehabilitation of the disabled is the restoration of the disabled person to the fullest possible physical, economic and social independence and usefulness. This restoration involves in a multifaceted activity involving the mobilisation of many disciplines in the medical, educational and vocational fields and the use of many agencies, official as well as non-official. This can be considered as consisting of medical rehabilitation, educational rehabilitation, vocational and economic rehabilitation leading to social rehabilitation and integration.

Medical rehabilitation includes the prevention or minimising of disabilities by the efficient treatment of the disabling conditions like poliomyelitis, accidental injuries, which will include fitting of orthopaedic appliances and artificial limbs, etc.

A child, disabled either by birth defects or by acquired conditions, like diseases and accidents, needs not only effort in medical rehabilitation but also continuing education during the time of prolonged treatment to prevent educational handicaps compared to children of equal age at school. Children with blindness, deafness and deaf-mutism and those with mental retardation and those with severe orthopaedic handicaps need facilities for special education.

As the disabled child reaches the school leaving stage, it has to be prepared to face life by providing vocational training in suitable occupations which again needs the creation of special institutional facilities with proper physical facilities and staff.

The handicapped person should not be called a disabled person but a person with a disability, as he has a large amount of potential abilities waiting to be developed and utilised.

The goal of all the above activities is to fit the young disabled person into suitable job, so that he will be a productive and socially useful citizen. This restores his self-respect, self-esteem and social acceptability with all its attendant, psychological satisfaction and sense of self-fulfilment.

It is obvious from the above that rehabilitation work on a national scale needs an enormous infrastructure—organisations with managerial and administrative talent and various types of mobilising the skills of many professional areas.

The type of work involved also cannot be managed by governmental effort alone. A good amount of community initiative and enterprise, committed and dedicated social leadership, and support from social workers at



field level are all essential to promote awareness and concern among the public, the private employers and philanthropists to provide the humanistic base and drive.

As a welfare state, India is committed to promote the welfare of the disabled and has to provide adequate arrangements for delivery of rehabilitation services to the disabled. As the many facets of the work are distributed to various agencies of the governmental machinery, the need for a proper coordinating organisation is obvious. One of the most difficult things in government is the coordination of any activity to implement goal oriented programmes.

I feel that a strong administrative set-up is essential at the policy making level as also at the execution level and there should be an effective set-up at the delivery point of the services at the community level right down to the rural areas.

I shall for a change start from the grassroot level and build upwards, reversing the usual planning procedure in our country which starts at the top and never reaches the bottom.

At the block and village level, the available delivery point of health services is the primary health centre covering a population of 100,000 with 3 to 4 sub-centres at village levels. There is a team of health professionals headed by a medical officer to promote health, prevent diseases and provide curative services. Although rehabilitation is mentioned in the health plan documents as the fourth item in health care, so far there has been no attempt to implement it on a broad basis.

It is essential to provide a person, trained in rehabilitation of the disabled, at the most peripheral outlet of health care administration so that he will be in direct touch with the consumer of rehabilitation service at the village level. He will be involved in disability prevention, basic therapy to minimise disabilities and also start a referral service for major disabilities. At the taluk (5 lakh population) and district (20 lakh population) there should be provision of institutional care for the disabled by the medical department. It is also necessary to provide special educational facilities for the blind, deaf and dumb and the severely orthopaedically handicapped at the district level.

A district with 20 lakh population will need an administrative set-up for the vocational and social rehabilitation of the disabled. This process involves vocational evaluation and vocational training and finally placement of the disabled in suitable jobs, and follow up. At this stage, the disabled persons also need mobility aids (hand operated tricycles, wheelchairs, artificial limbs and appliances for the orthopaedically handicapped, hearing aids for the hearing handicapped and special walking sticks for the visually handicapped). The above package of services extending beyond the hospital premises again needs an effective organisational base at the district level.



## DISTRICT ORGANISATION

A district rehabilitation council with representation from all the concerned government departments as well as from the voluntary agencies like the Red Cross, Lions Clubs and Rotary Clubs will be useful to effectively promote rehabilitation, by mobilising governmental and the non-official voluntary agencies.

Such organisations at the district level need the administrative support at the state level if they have to function effectively. Here, the directorates of social welfare, medical and health services, directorates of education as well as industries have to be coordinated by the government to give the necessary dynamism generated by the political will of the party in power. In my opinion, the execution of policies is better undertaken by a statutory board or corporation rather than a regular government department. This will avoid the procedural delays and the rigid inflexibilities of the governmental machinery, where the need is for urgent decision regarding the individual needs of the disabled persons.

I shall give a simple example. An application by a severely disabled person for a wheelchair or an artificial limb will require his running from office to office for months in search of an income or eligibility certificate if he is made to follow governmental procedure enshrined in the departmental codes laid down in 1885. An autonomous corporation or board could simplify the procedure and provide prompt service to the needy individual.

At the political level, the state policies and goals for the rehabilitation of the disabled will be spelt out by a state ministerial commission/committee for the handicapped. Such a state commission of ministers for the disabled will command the necessary compliance at the administrative level.

It will be obvious that in a vast country like India with states at varying levels of development, it is necessary to have a national policy for the disabled as recommended by the United Nations. Disability in a population is a national problem and it needs the strength of the national political will as well as the resources of the central government to provide the dynamism to any programme to be carried out on a long term basis.

A national commission under the chairmanship of the Prime Minister will command the necessary authority to spell out the philosophy for a massive programme for the rehabilitation of the disabled. Social change requires not only material inputs but also the generation of emotional energy of committed individuals with a feeling of urgency.

Policies in the field of rehabilitation need action at the legislative, executive as well as operational or field level. A national level monitoring set-up is also necessary to obtain feedback information to help evaluation of the programme.



*SUGGESTED CHART FOR NATIONAL ORGANISATION*  
INTERNATIONAL YEAR OF THE DISABLED PERSONS 1981

NATIONAL COMMISSION FOR THE HANDICAPPED

Chairman : Prime Minister



STATE COMMISSION/COMMITTEE FOR THE HANDICAPPED

Chairman : Chief Minister  
Dy. Chairman : Finance Minister

Ministers of Health;  
Social Welfare; Education;  
Labour and Employment.



STATE BOARD FOR THE HANDICAPPED (STATUTORY)

Chairman : Finance Minister  
Secretary : Secretary, Social Welfare Department.

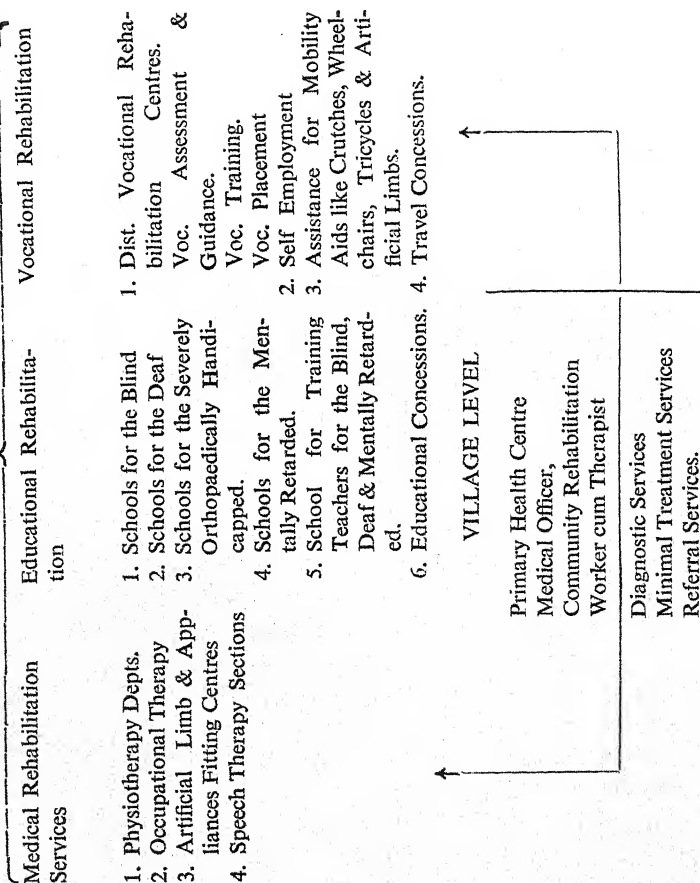
Directors of Social Welfare, Medical Services, Medical Education, and Industries  
and Non-Officials.





↑  
DISTRICT COUNCIL FOR THE HANDICAPPED

District Collector, D.M.O., D.H.O., D.W.O., Municipal Commissioners,  
Block Development Officers, *Non-Officials*: Indian Red Cross, Lions and  
Rotarians, College Principals, etc.





Legislative measures are preferable to executive orders as the legal basis provides permanent and continuous stimulus for action for the disabled.

### MAIN POINTS

To sum up, the first requirement for a rehabilitation of the 65 million disabled population of our country is the existence of a committed philosophy enshrined in the constitution of the country. The international stimulus can succeed only in the presence of such a commitment. This has already been done and included in the directive principles of the constitution. The next requirement is the political will at the national level to spell out the philosophy into achievable policies. Such policies have to be translated into goal oriented plan frames. Such plan frames have to take into account priorities and strategies as the advance of any sector of the population depends on the overall advance of all sectors and their interaction.

As health education and social welfare are state subjects, the successful implementation of such plans depends on the existence of state governments equally committed to the philosophy and equally geared to the implementation of the policies and plans. It is well known that the states in our country are not all at the same level of development and do not have the same degree of infrastructure facilities to translate policies into action programmes. Hence, the national policy and plan should have enough flexibility and permit and encourage the states to initiate programmes without rigidly requiring uniformity in implementation. Thus the state with a high literacy level like Kerala should not be compelled to fall in line with states like Bihar and Uttar Pradesh in carrying out programmes at the field level. Hence, there is need for planning bodies at state level to take into account local conditions. For example, the starting of medical rehabilitation facilities at district, taluk or primary care levels depends on the presence of efficient infrastructural health care institutions with trained manpower at these levels.

Some states, for instance, will have to be helped to start training institutions for physical medicine specialists and physiotherapists; states like Maharashtra and Tamil Nadu which have started such institutions twenty years ago should be encouraged to train a large number of field level paramedical workers who could function at the village and taluk levels and refer the patients with disabilities to bigger institutions at taluk and district levels.

Rehabilitation of the handicapped is a service oriented activity unlike the production of material assets like coal or steel. The strategies and tactics in reaching goals in this field have to mobilise certain human forces in the community. This is in the form of active participation of community leaders and voluntary agencies which provide the emotional and popular drive to the programmes sanctioned, initiated and monitored by the official machinery.





## Measuring Disability States in the Context of Service Provision: A Survey

Miron Mushkat

THE NEEDS of the disabled have been accorded official recognition in many contemporary societies. A fair number of governments can, in fact, be credited with putting into operation a portfolio of rather elaborate policy measures designed to improve their welfare.<sup>1</sup> This notwithstanding, resources for managing problems of the disabled continue to be limited and are likely to become increasingly so in the stagflationary period which lies ahead. As a corollary, public authorities are bound to seek measurement tools that would enable them to differentiate between various degrees of disability and ration resources<sup>2</sup> accordingly (*i.e.*, to identify priority areas and provide more for those whose needs are most apparent than for those whose needs seem somewhat less urgent).

Such instruments may also be required because of the growing emphasis on accountability in the provision of social (or, for that matter, any public) services.<sup>3</sup> The reason lies in the indifferent performance of social programmes as well as the scarcity of resources. Both factors have combined to create a decision-making climate which puts a high premium on the *real* impact of social intervention. Programme outcomes are now carefully monitored (under the banner of 'performance audit')<sup>4</sup> in many of the social services

<sup>1</sup>For example, see: J. Wiseman and J. Cullis, "Social Policy towards Disabled Workers", in A.J. Culyer (ed.), *Economic Policies and Social Goals*, London, Martin Robertson, 1974, pp. 138-170. M. Berkowitz *et al.*, *An Evaluation of Policy Related Rehabilitation Research*, New York, Praeger, 1975; E. Topliss, *Provision for the Disabled*, Oxford, Basil Blackwell, 1975. M. Berkowitz *et al.*, *Public Policy toward Disability*, New York, Praeger, 1976. G. Laurie, *Housing and Home Services for the Disabled*, New York, Harper and Row, 1977; I. Howards, H.P. Brehm and S.Z. Nagi, *Disability*, New York, Praeger, 1980.

<sup>2</sup>For a discussion of rationing in the social services, see: M.H. Cooper, *Rationing Health Care*, London, Croom Helm, 1975. K. Judge, *Rationing Social Services*, London, Heinemann, 1978.

<sup>3</sup>For a discussion of this point, see: M. Mushkat, "Management-by-Objectives in the Provision of Social Services", *Indian Journal of Public Administration*, XXVI, July-September, 1980, pp. 663-683.

<sup>4</sup>See, in this connection; M. Holzer (ed.), *Productivity in Public Organizations*, Port Washington, Kennikat Press, 1976, F. Pomeranz *et al.*, *Auditing in the Public Sector*, New York, Coopers and Lybrand, 1976, R. N. Anthony and R. Herzlinger, *Management Control in Nonprofit Organizations*, Homewood, Irwin, 1980.





and the work carried out in the United Kingdom (especially at the University of York Institute of Social and Economic Research) suggests that programmes for the disabled may well be subjected to closer scrutiny in the not too distant future. The question is: Are the disabled benefiting in any tangible way from the services extended to them? And to answer this question social planners need measurement tools that would make it possible to distinguish between different disability states with a view to establishing whether programme intervention indeed results in progressive movement of recipients from one state to another (improvement) or at least absence of excessive deterioration.

Above all, however, instruments for measuring disability states are indispensable to the undertaking of basic diagnostic activities. Contrary to what may be generally assumed, the disabled are a highly heterogeneous group and the symptomatology associated with their condition manifests itself in such a multitude of forms that even skilled diagnosticians find the task most challenging.<sup>5</sup> The systems approach to disability<sup>6</sup> accords to correct diagnosis a central role in the habilitation and rehabilitation of the disabled. And correct diagnosis hinges on the availability of a whole range of sophisticated measurement tools in the hands of the embattled social service professionals.

In some respects, of course, the measurement of disability states is a well-established enterprise. For there can be little doubt that, although serious difficulties still remain,<sup>7</sup> the progress recorded in the medical evaluation of both the physically and intellectually handicapped has been very considerable.<sup>8</sup> Be that as it may, medical data in themselves furnish only a fraction of the information required for identifying and assessing the needs of the disabled, allocating resources to meet these needs and monitoring

<sup>5</sup>For example, see: P.J.R. Nichols, "Assessment of the Severely Disabled", in D.M. Boswell and J.M. Wingrove (eds.), *The Handicapped Person in the Community*, London, Tavistock, 1974, pp. 366-376.

<sup>6</sup>See, in this connection, I.H. Bermingham, "Organisation and Development", in *ibid*, pp. 408-414.

<sup>7</sup>These difficulties are discussed in : P.J.R. Nichols, *op. cit.*

<sup>8</sup>For example, see: Committee on Medical Rating of Mental and Physical Impairment, American Medical Association, "Guides to the Evaluation of Permanent Impairment", *Journal of the American Medical Association*, 166, February, 1958, pp. 3-109. W.C. Smith, *Principles of Disability Evaluation*, Philadelphia, Lippincott, 1959. S.C. Franco, "Disability Evaluation", *Journal of Occupational Medicine*, 2, September, 1963, pp. 433-442. E.D. McBride, *Disability Evaluation and Principles of Treatment of Compensable Injuries*, London, Pitman, 1963. Committee on Medical Rating of Mental and Physical Impairment, American Medical Association, "Guides to the Evaluation of Permanent Impairment", *Journal of the American Medical Association*, 202, November, 1967, pp. 624-639. C.O. Rice, *Calculation of Industrial Disabilities of the Extremities and the Back*, Springfield, Thomas, 1968. H.H. Kessler, *Disability*, Philadelphia, Lea and Febiger, 1970. S.Z. Nagi, *Disability and Rehabilitation*, Columbus, Ohio State University, 1970. R.M. Goldenson *et al.*, *Disability and Rehabilitation Handbook*, New York, McGraw-Hill, 1978.



progress. Social planners and service providers ought to have at their disposal a far more extensive data base than that which the medical profession is capable of supplying them with.<sup>9</sup> Indeed, studies conducted in recent years have largely focused on measuring disability states in non-clinical terms. The aim of this article is to review the work done and to appraise it.

### AN OVERVIEW

Attempts to measure disability states in non-clinical terms are about two decades old. The research carried out in this area has entered a consolidation phase only in the 1970s, but important strides were made already in the 60s.<sup>10</sup> Typical in that respect was the 'Index of Independence in Activities of Daily Living' (Index of ADL) developed by Katz and his asso-

<sup>9</sup>The importance of information in decision-making in the social services is highlighted in C.W. Cobb, "A Management Information System for Mental Health Planning and Program Evaluation", *Community Mental Health Journal*, 7, December, 1971, pp. 280-287. J.R. Elpers and R.L. Chapman, "Management Information for Mental Health Services", *Administration in Mental Health*, 1, Fall, 1973, pp. 12-25. J.L. Crawford, D.W. Morgan and D.T. Giantucco (eds.), *Progress in Mental Health Information Systems*, Cambridge, Ma., Ballinger, 1974. C.N. Edwards and P.P. Schmitt, "Case-Oriented Information Systems", *Evaluation*, 2, January, 1974, pp. 65-67. B. Miller, G.H. Miller and L. Cantrell (eds.), *Information and Feedback for Evaluation*, Toronto, York University, 1975. A.S. Weinstein, "Evaluation through Medical Records and Related Information Systems", in E.L. Struening, and M. Guttentag (eds.), *Handbook of Evaluation Research*, Beverly Hills, Sage, 1975, pp. 397-481. S.J. Bernstein (ed.), *Computers in Public Administration*, New York, Pergamon, 1976. T.P. Holland, "Information and Decision Making in Human Services", *Administration in Mental Health*, 4, Fall, 1976, pp. 26-35. National Institute of Mental Health, *The Design of Management Information Systems for Mental Health Organizations*, Washington, D.C., Government Printing Office, 1976. J. Herson *et al.*, "FP/MIS", *Medical Care*, 15, May, 1977, 409-418. G.H. Miller and B. Willer, "An Information System for Clinical Recording, Administrative Decision Making, Evaluation and Research", *Community Mental Health*, 13, June, 1977, pp. 194-204. A. Broskowski, J. Driscoll and H.C. Schulberg, "A Management Information System for Indirect Services", in C.C. Attkison *et al.*, (eds.), *Evaluation of Human Service Programs*, New York, Academic Press, 1978, pp. 189-211. H.R. Catherwood, "Management Information System for Social Services", in S. Slavin (ed.), *Social Administration*, New York, Haworth Press, 1978, pp. 493-505. J.M. Donahue *et al.*, "The Social Service Information System", in *ibid.*, pp. 481-492. J. R. Elpers and R.L. Chapman, "Basis of the Information System Design and Implementation Process", in C.C. Attkison *et al.*, *op. cit.*, pp. 173-188. J.E. Sorensen and J.R. Elpers, "Developing Information Systems for Human Service Organizations", in *ibid.*, pp. 127-172. D.W. Young, "Management Information Systems in Child Care", in S. Slavin, *op. cit.*, pp. 504-514. D. Davis and R. Allen, "The Evolution of a Management Information System in an Outpatient Mental Health Institute", *Administration in Mental Health*, 6, Spring, 1979, pp. 225-239.

<sup>10</sup>It is instructive to compare the investigations undertaken over the past two decades with the symptom-oriented enquiries of the 1950s. For example, see: W. Hobson and J. Pemberton, *The Health of the Elderly at Home*, London, Butterworth, 1955.



ciates<sup>11</sup> in 1963<sup>12</sup> at Cleveland's Benjamin Rose hospital. The Index is not grounded in conventional clinical nomenclature; rather, it purports to measure the *adequacy of performance* ("functional capacity") insofar as the *execution of the activities of daily living* (i.e., activities which people perform habitually and universally) is concerned.

Six activities/functions comprise the Index of ADL: bathing, dressing, going to toilet, transferring, continence and feeding. Adequacy of performance is expressed as a grade<sup>13</sup> (A, B, C, D, E, F, G or other) which summarises the overall performance in these functions (Annexures 1 and 2). The bulk of the disabled evaluated by means of the Index have tended to cluster in the following categories: (1) independent, (2) dependent in bathing, (3) dependent in bathing and dressing, (4) dependent in bathing, dressing and going to toilet, (5) dependent in bathing, dressing, going to toilet and transferring, (6) dependent in bathing, dressing, going to toilet, transferring and continence, and (7) dependent in bathing, dressing, going to toilet, transferring, continence and feeding.<sup>14</sup>

Although the Index of ADL was primarily developed from empirical observations of a large number of activities performed by a group of patients with fracture of the hip, the six functions singled out and their characteristic order have considerable theoretical significance. The Index, in fact, reflects both identifiable patterns of child growth and the behaviour of members of primitive societies. Pediatric tests for one describe the development of children in terms of feeding, elimination, locomotion, going to toilet and bathing.<sup>15</sup> Terms used in the Index, which was designed independently, are very similar.

On a more general level, pediatric authorities<sup>16</sup> distinguish between vegetative and culturally learned behaviours, and an analogous distinction can be recognised in the activities of the Index of ADL. The definitions in the Index of feeding, continence and transfer thus closely mirror the organised locomotor and neurological aspects of simple vegetative functions, exclusive of their more complex cultural and learned characteristics. As

<sup>11</sup>S. Katz, *et al.*, "Studies of Illness in the Aged", *Journal of the American Medical Association*, 185, September, 1963, pp. 914-919.

<sup>12</sup>The Index was, in fact, eight years in the making.

<sup>13</sup>That is, ordinal measurement is employed.

<sup>14</sup>The Index can thus be more appropriately described as a Guttman scale. The subtle difference between indexes and scales is succinctly explained in: T.H. Poister, *Public Program Analysis*, Baltimore, University Park, 1978. The use of Guttman scales in measuring disability states is discussed in: R.L. Berg (ed.), *Health Status Indexes*, Chicago, Hospital Research and Educational Trust, 1973. A.J. Culyer, "Need, Values and Health Status Measurement", in A.J. Culyer and K.G. Wright (eds.), *Economic Aspects of Health Services*, London, Martin Robertson, 1978, pp. 9-31.

<sup>15</sup>For example, see: A. Gesell and F.L. Ilg, *Infant and Child in Culture of Today*, New York, Harper, 1943. M. Almy, *Child Development*, New York, Holt, 1955.

<sup>16</sup>See, in this connection, S. Katz, *et al.*, *op. cit.*



defined in the Index, on the other hand, going to toilet, dressing and bathing also require organised locomotor and neurological functioning, but these activities are strongly influenced by cultural factors and learning.

The correspondence between the recovery of function in the disabled, which provided the conceptual underpinning for the Index of ADL,<sup>17</sup> and the progression of function in the growing child is unmistakable. By the age of 2, the child holds a glass securely and takes food into his mouth on a spoon.<sup>18</sup> He is not yet completely continent and requires a great deal of assistance and supervision in dressing and bathing. By the age of 3, he feeds himself and can even pour a pitcher. Nights of wetness occur, and supervision of going to toilet is required in managing clothes and in self-cleansing. The 3½-year-old child is generally dry at night. By the age of 4, he uses the toilet independently, though he may still require occasional supervision. Between the ages of 4 and 5, he requires only general supervision in dressing and bathing. The parallel with the order of return for the disabled patient is evident and suggests that common biological mechanisms underlie the two kinds of progression.<sup>19</sup>

Anthropology furnishes independent confirmation of the biological primacy of the functions which comprise the Index of ADL. Here again, a distinction is evident between vegetative and culturally learned activities.<sup>20</sup> All peoples, primitive and advanced, develop self-regulation of feeding and elimination as prerequisites for survival. They also develop independent locomotion, moving from one place to another to adapt themselves and their environments to their needs. Dressing and bathing, however, are not necessities of day-to-day physiological functioning, as evidenced by the habits of

<sup>17</sup>Katz and his team noted that recovering patients passed through three stages: an early recovery of independence in feeding and continence; subsequent recovery of transfer and going to toilet; and lastly, often after discharge, the recovery of complete independence in dressing and bathing.

<sup>18</sup>For example, see: A. Gesell and F.L. Ilg, *op. cit.*, A. Gesell, *First Five Years of Life*, New York, Harper, 1940.

<sup>19</sup>It might also be hypothesised that, just as there is an orderly pattern of development, there is an ordered regression as part of the natural process of aging. It seems reasonable that loss of function would begin with those activities which are most complex and least basic, while those functions which are most basic and least complex would be retained to the last. Limited observations made by Katz and his associates in the course of their work would tend to confirm this hypothesis. All of their subjects, however, had become disabled prior to entering the studies, and elucidation of the natural patterns of deterioration would require study of 'well' old people. The Index of ADL does provide an objective approach to such a study of the aging process if one considers aging as a composite of a number of deteriorating physiological functions. Katz *et al.*, argue that such a study might lead to the fulfilment of Gesell's prediction that "the laws of association will some day be reformulated in terms of the biology and physiology of development". See, in this connection, A. Gesell, *Studies in Child Development*, New York, Harper, 1948.

<sup>20</sup>For example, see: G.P. Murdock, *Our Primitive Contemporaries*, New York, Macmillan, 1934, W.L. Warner, *Black Civilization*, New York, Harper, 1937.



children of primitive groups.<sup>21</sup> Modified forms of dressing and bathing are, nonetheless, performed regularly and universally even by primitive peoples, as in the use of arm band, body string, fur, headdress, loincloth, mask, necklace and the taking of ritual bath.<sup>22</sup> The cultural significance of dressing and bathing is emphasised by the ceremonial and symbolic use of dress to express courage, rank, sexual maturity and strength, and by the practice of bathing to clean away evil.<sup>23</sup>

The Index of ADL stands out amongst the measurement instruments developed in the 60s because of its solid empirical and theoretical foundations. Another pivotal tool which came into use in the same period is the *measure of incapacity for self-care* designed by Townsend.<sup>24</sup> The measure revolves around activities (and is also, therefore, as are practically all the instruments intended for this purpose, a measure of functional capacity) which a disabled person living alone would be obliged to perform and the faculties<sup>25</sup> he would have to employ to maintain life, assuming he received no assistance. The activities fall into four categories (Annexure 3): (1) those which are always, or nearly always, performed by the disabled person if he is able to do them, (2) those which may be done by others even when the disabled person is able to do them (but which have to be done by him if no help is available), (3) those faculties which have to be employed for the purpose of social communication, and (4) those activities or tasks which have to be done only when the individual suffers from some special disabling condition (as, for instance, the injections and the preparation of special foods for those with diabetes). The disabled person's capacity to perform each of the activities encompassed by the measure is scored with one of the figures 0, 1 or 2 (thus taking at least some account of the *degree* of incapacity). In theory the total score can range from 0 to well over 20; in practice Townsend<sup>26</sup> found the range to be from 0 to 18. A disabled person scoring 0 is regarded as being fully capable of looking after himself; one scoring from 12 to 18 is regarded as being able to do little or nothing for himself.<sup>27</sup>

<sup>21</sup>For example, see: G.P. Murdock, *Our Primitive Contemporaries*, *op. cit.*

<sup>22</sup>For example, see: *Ibid.*

<sup>23</sup>For example, see: *Ibid.*

<sup>24</sup>P. Townsend, *The Last Refuge*, London, Routledge and Kegan Paul, 1962.

<sup>25</sup>The faculties singled out are again closely related to a disabled person's functional capacity and can, in fact, be subsumed under the term 'activities'.

<sup>26</sup>It should be noted, in this connection, that his sample was confined to residents of homes and institutions for the aged.

<sup>27</sup>Specifically, the scores can be interpreted as follows:

Score	Interpretation
0—2	Needs little help to live alone in own home.
3—5	Needs a slight amount of help to live alone in own home.
6—8	Needs substantial help to live alone in own home.
9+	Needs very substantial and continuous help from others living at home or close at hand.



The measure of incapacity for self-care differs from the Index of ADL in that it goes beyond *rank-ordering* disability states and provides *quantitative scores*. This is also true of the *Maryland Disability Index* (occasionally referred to as the *Barthel Index*),<sup>28</sup> perhaps the most widely used amongst the instruments developed in the 1960s for measuring the functional capacity of the disabled. That Index had evolved from the work carried out in Maryland's three chronic disease hospitals over a nine-year period. It is somewhat more compact than the measure of incapacity for self-care and assigns 5, 10 and 15 points for each of a number of activities of daily living, producing a total of 100 points when all activities are carried out adequately (Annexure 4).

The score for each activity in the *Maryland Disability Index* was derived on an empirical basis. A physical therapist and a psychiatrist discussed informally with nurses and physicians involved in work with the disabled the importance of each activity to the patient, and in reducing the need for nursing and personal care. Recognising this arbitrary means of instrument development, the two made no attempt to refine scores to values less than 5 points, nor to employ intermediate scores between 5, 10 and 15 points. They did, however, standardise the scoring instructions to define as unambiguously as possible the conditions under which each score was to be given (Annexure 5).

The Index of ADL, the measure of incapacity for self-care and the Maryland Disability Index have proved themselves effective in a wide variety of contexts. Indeed, the measurement instruments developed in the 70s bear close resemblance to their predecessors both in terms of underlying logic and actual form. The difference between the two decades lies in the fact that the studies undertaken in the 70s usually involved larger populations and that throughout the decade a number of attempts were made to consolidate the results of past research<sup>29</sup> in addition to generating new indexes and scales; otherwise, the focus of the design effort had remained very much the same.

The number of measurement instruments developed in the 70s is fairly large. The ones that have attracted perhaps the greatest attention in pro-

<sup>28</sup>See: C.M. Wylie and B.K. White, "A Measure of Disability", *Archives of Environmental Health*, 8, June, 1964, pp. 834-839.

<sup>29</sup>In particular, see: J. Garrad, "Impairment and Disability", in D. Lees and S. Shaw (eds.), *Impairment, Disability and Handicap*, London, Heineman, 1974, pp. 141-156. K.G. Wright, "Alternative Measures of the Output of Social Programmes", in A.J. Culyer, *op. cit.*, pp. 239-272. A.J. Culyer, *Need and the National Health Service*, London, Martin Robertson, 1976. A.J. Culyer, "Needs, Values, and Health Status Measurement", in A.J. Culyer and K.G. Wright (eds.), *Economic Aspects of Health Services*, London, Martin Robertson, 1978, pp. 9-31. K.G. Wright, "Output Measurement in Practice", in *ibid.*, pp. 46-64.





fessional circles are those produced by Sainsbury,<sup>30</sup> Carstairs and Morrison,<sup>31</sup> Garrad and Bennett,<sup>32</sup> and Harris *et al.*<sup>33</sup> (The work of the Buckle<sup>34</sup> and the US Department of Health, Education and Welfare<sup>35</sup> is also worth-mentioning). The Sainsbury *measure of incapacity* (Annexure 6), the Carstairs and Morrison *description of dependency categories* (Annexure 7), the Garrad and Bennett *measure of disability* (Annexure 8), and the Harris *disability index* (Annexure 9) are to be found at the end of this article. They all centre on the functional capacity of the disabled and aim at<sup>36</sup> either rank-ordering or quantitative scoring of performance. The mechanics of their construction is not discussed in any detail here because of the general similarity to the three earlier instruments. The appraisal that follows, however, applies as much to them as to the products of the 1960s.

### AN APPRAISAL

The work reviewed in the preceding section constitutes a major step forward in the measurement of disability states. Conventional clinical systems, which simply do not meet the multifarious needs of social planners and service providers, have been supplemented over the past two decades by an impressive range of instruments that shift the analytical focus from symptom-description to assessment of functional capacity. There can be little doubt that these instruments go a long way towards providing a firmer basis for decision-making concerning the disabled.

In fact, disability is defined now in strictly functional terms as "limitation of performance for one or more activities essential in daily living such that the person is dependent on others, and severity of disability is proportional to dependence."<sup>37</sup> (For the anatomical, pathological and psychological disorders which may cause or be associated with disability the

<sup>30</sup>S. Sainsbury, *Registered as Disabled*, Londin, Bell, 1970, S. Sainsbury, *Measuring Disability*, London, Bell, 1973.

<sup>31</sup>V. Carstairs and M. Morrison, *The Elderly in Residential Care*, Edinburgh, Scottish Home and Health Department, 1971.

<sup>32</sup>J. Garrad and A.E. Bennett, "A Validated Interview Schedule for Use in Population Surveys of Chronic Disease and Disability", *British Journal of Preventive and Social Medicine*, 25, May, 1971, pp. 97-104.

<sup>33</sup>A. Harris *et al.*, *Handicapped and Impaired in Great Britain*, London, Office of Population Censuses and Surveys, Her Majesty's Stationery Office, 1971.

<sup>34</sup>J.R. Buckle, *Work and Housing of Impaired Persons in Great Britain*, London, Office of Population Censuses and Surveys, Her Majesty's Stationery Office, 1971.

<sup>35</sup>Social Security Administration Office of Research and Statistics, U.S. Department of Health, Education and Welfare, *The Social Security Disability Program—An Evaluation*, Washington, D.C., Government Printing Office, 1971.

<sup>36</sup>With the exception of Garrad and Bennett who confine themselves to nominal measurement.

<sup>37</sup>See: A.E. Bennett, J. Garrad and T. Hill, "Chronic Disease and Disability in the Community", *British Medical Journal*, September 26, 1970, p. 762.



term *impairments* is employed. These may be classified into four categories: those affecting locomotion or any motor activity, those of sensory origin, those referable to internal medicine—for instance, cardiac and respiratory disorders—and those of primarily psychological origin together with unclassifiable organic disorder.)<sup>38</sup> The virtue, therefore, of the work surveyed above lies not only in its usefulness of social administrators but also in the close correspondence between its empirical constructs and the emerging concept of disability.<sup>39</sup>

It is, of course, possible to gauge functional capacity by means of instruments other than the standard tests of performance and interview schedules of the kind described here—which invariably revolve around activities of daily living. The main alternative would be the highly developed and vigorously tested measures of *motor capacity*.<sup>40</sup> These measures are based on the premise that the components of actions which we perform in our daily lives can effectively be isolated, and the capacity to perform them can be used as an indicator of capacity to meet all requirements of daily life. Motor capacity may be tested in standard situations—people are asked to step on and off a platform of a certain height, to touch the floor from a chair of a certain height, to lift articles of a specified weight and so on. Such standard actions are held, on balance, to be broadly representative of those which the majority of people perform most of the time. Motor capacity may be assessed in this way against an objective criterion such as time. It is assumed for the purposes of assessment that differences in height, weight and other similar attributes between the individuals whose capacity is tested, make little difference to the validity of the exercise.

Measures of motor capacity, however, have a number of serious drawbacks.<sup>41</sup> In the first place, it is arguable that in identifying and assessing needs in the context of service provision, the *sum* of a person's difficulties,

<sup>38</sup>See, in this connection, A.E. Bennett, J. Garrad and T. Hill, "Chronic Disease and Disability in the Community", *op. cit.*

<sup>39</sup>Which obviously differs substantially from the popular concept of a disabled person as "someone who has lost a limb or who is physically deformed in some obvious way. This concept is largely based on the appreciation of structural damage; severity is considered to be dependent on the extent of the damage and criteria based on this approach govern the assessment and award of the disability pensions at present available. However, disability may be thought of in terms of behaviour and performance and may be considered as limitation of the performance of an individual when compared to a 'fit' person. This concept considers disability as a disorder of function rather than a structural abnormality or loss". See: J. Garrad and A.E. Bennett, "A Validated Interview Schedule for Use in Population Surveys of Chronic Disease and Disability", *British Journal of Preventive and Social Medicine*, 25, May, 1971, p. 97.

<sup>40</sup>For example, see: D. Carroll, "A Quantitative Test of Upper Extremity", *Journal of Chronic Diseases*, 18, May, 1965, pp. 479-491. M. Jeffreys *et al.*, "A Set of Tests for Measuring Motor Impairment in Prevalence Studies", *Journal of Chronic Diseases*, 22, November, 1969, pp. 303-320.

<sup>41</sup>For a discussion, see: S. Sainsbury, *Measuring Disability*, *op. cit.*





only one of which may be motor incapacity, should be taken into account. For instance, by concentrating on a single facet of disability, a measure of motor capacity largely excludes problems such as mental coordination and exhaustion. Second, an assessment of motor capacity may fail to identify certain members of the disabled population whose disability does not originate in motor incapacity. Thus, it may be possible for a mentally handicapped person to carry out the simple exercises designed to assess motor capacity, but to experience difficulty in accomplishing minimal activities for daily living. There is a third drawback in relying entirely on measures of motor capacity to define and assess disability: attention tends to focus exclusively on the most severely disabled persons. Degrees of motor capacity indicate functional achievement only of those who experience difficulty at the most basic level, that is, in relation to "eating, drinking, urinating and defaecating hygienically, washing, and dressing and undressing, sitting, standing, stepping up and down and walking a few steps."<sup>42</sup> Severe bronchitis may allow a person to achieve all these daily tasks, but it may still make an enormous impact on a person's capacity to function in daily life.

For these reasons, measures based on performance of activities of daily living are generally preferable to those of motor capacity. The former, as can be seen here, tend to centre in one way or another on four broad clusters of activities: (1) mobility: walking, negotiating steps, transfer in and out of bed or chair and travel, (2) self-care: feeding, dressing and toilet care, (3) domestic duties: shopping, preparation and cooking of food, household cleaning, clothes-washing, and (4) occupation: the ability to hold unmodified employment in open industry appropriate to the individual's age, sex and skill. As can be expected, the instruments developed over the past two decades vary in emphasis in accordance with the specific objectives of their designers but, taken together, they provide a satisfactory spread insofar as these focal activities are concerned.<sup>43</sup>

The question arises, however, whether it is desirable to confine instrument development to activities which pertain solely to the physical and economic dependence of the disabled. It is true that both conditions are the most visible by-products of disability and that social policy is more con-

<sup>42</sup>See: M. Jeffreys *et al.*, *op. cit.* p. 303.

<sup>43</sup>The sole possible exception to that generalisation is the occupation category which does not loom large enough in the work referred to (far greater heed seems to have been paid to activities that relate to *physical* dependence than those that relate to economic dependence). The importance of employment in the context of disability is highlighted in: P.J. Taylor and A.J. Fairrie, "Chronic Disabilities and Capacity for Work", *British Journal of Preventive and Social Medicine*, 22, April, 1968, pp. 86-93; P.J. Taylor and A.J. Fairrie, "Chronic Disability in Men of Middle Age", *British Journal of Preventive and Social Medicine*, 22, October, 1968, pp. 183-192; S.Z. Nagi, W.H. McBroom and J. Collette, "Work Employment and the Disabled", *American Journal of Economics and Sociology*, 31, January, 1972, pp. 21-34; L.D. Haber, "Social Planning for Disability", *Journal of Human Resources*, VIII, Supplement, 1973, pp. 33-55.



cerned with them than with other forms of deprivation. At the same time, the disabled also often suffer from psychological and social handicaps which are serious enough to warrant attention in the context of service provision.<sup>44</sup> There is, of course, no dearth of instruments for measuring psychological adjustment but it would be fair to say that we simply do not have the necessary tools to shed light on the quantity and quality of social relations of those caught in circumstances of disability.<sup>45</sup> The work of Townsend<sup>46</sup>, Tunstall<sup>47</sup>, Shanas, *et al*<sup>48</sup>, and Wright<sup>49</sup> on the prevalence of social isolation amongst old people might serve as a possible model in developing such tools.

There is another point. All the instruments reviewed here are unduly restricted to the normative dimension of need. (Following Bradshaw<sup>50</sup> it is common to distinguish between *normative* need, *felt* need, *expressed* need and *comparative* need. Normative need is what the expert or professional, the administrator or social scientist defines as need in a given situation. Felt need is equated with *want*; when identifying and assessing need for a service, people are asked whether they feel they need it. Expressed need or *demand* is felt need turned into action. Lastly, comparative need is found by studying the characteristics of those in receipt of service; if people with similar characteristics are not in receipt of a service, then they are in need.) Most researchers conceive of disability in terms of physical and economic dependence; others put accent on its psychological and social aspects. A case might be put forward, however, that the disabled themselves should provide a significant input to the process of need identification and assessment and that instrument development ought to be somehow embedded in the concept of felt need.<sup>51</sup> By working more closely with potential service recipients,

<sup>44</sup>For example, see: B.A. Wright, *Physical Disability*, New York, Harper and Row, 1960. H.R. Kelman and A. Willner, "Problems in Measurement and Evaluation of Rehabilitation", *Archives of Physical Medicine and Rehabilitation*, 43, April, 1962, 172-181.

<sup>45</sup>Few, for example, of the numerous questionnaires and interview schedules included in Miller's comprehensive handbook appear to be suitable for this purpose. See, in this connection; D.K. Miller, *Handbook of Research Design and Social Measurement*, New York, McKay, 1977.

<sup>46</sup>P. Townsend, *The Family Life of Old People*, Harmondsworth, Penguin, 1963.

<sup>47</sup>J. Tunstall, *Old and Alone*, London, Routledge and Kegan, 1966.

<sup>48</sup>E. Shanas *et al.* *Old People in Three Industrial Societies*, London, Routledge and Kegan, 1968.

<sup>49</sup>K.G. Wright, "Alternative Measures of the Output of Social Programmes", *op. cit.*; K.G. Wright, "Output Measurement in Practice", *op. cit.*

<sup>50</sup>J. Bradshaw, "The Concept of Social Need", *New Society*, 30, March, 1972, pp. 640-643.

<sup>51</sup>Indeed, it has been argued in this connection that "[T]here is a real danger of a new tyranny which sincerely expresses itself in the language of humanitarianism and which imposes its own values on others for what it sees to be their own good.... [We should be concerned with] delineating the question of what is expertise and what concealed class morality, and what is actual performance rather than unrealisable ethical intent.... It is my own opinion that the professions' role in a free society should be limited to contributing the technical



researchers could possibly discover additional forms of deprivation suffered by the disabled and design measurement tools accordingly.

The third, and final, point concerns methodology. For although the instruments developed over the past two decades have been constructed with utmost care, their originators have largely relied on a combination of extensive experience and intuitive grasp of the problem of functional incapacity rather than on formal rules of instrument design. This applies with equal force to the scales, which aim at rank-ordering disability states, and the indexes, which purport to yield quantitative-scores. The former have been put together without recourse to techniques of Guttman Scaling<sup>52</sup> and the latter without making use of any of the standard methods which are customarily employed in assigning index numbers of health states (these methods are: the *category method*<sup>53</sup>, the *magnitude method*<sup>54</sup>, the *equivalence method*<sup>55</sup>, the *standard gamble method*<sup>56</sup> and the *time trade-off method*<sup>57</sup>).

Cardinal measurement holds some distinct advantages over its ordinal counterpart<sup>58</sup>, but the informality with which the scoring systems of the indexes have been constructed is particularly problematic (it might be argued,

(Continued from previous page)

information men need to make their own decisions on the basis of their own values. When he preempts the authority to direct, even constrain men's decisions on the basis of his own values, the professional is no longer an expert but rather a member of a new privileged class disguised as an expert". See : E. Friedson, *Profession of Medicine*, New York, Dodd, Mead, 1970, pp. 381-382.

<sup>52</sup>The usefulness of these techniques is illustrated in: R.L. Berg, *op. cit.*; A.J. Culyer, *Need and the National Health Service*, *op. cit.*; A.J. Culyer, "Need, Values and Health Status Measurement", *op. cit.*; K.G. Wright, "Output Measurement in Practice", *op. cit.*

<sup>53</sup>See, in this connection, A.J. Culyer, "Need, Values and Health Status Measurement", *op. cit.*; D.L. Patrick, J.W. Bush and M.M. Chen, "Methods of Measuring Levels of Well-being for a Health Status Index", *Health Services Research*, 8, Fall, 1973, pp. 228-245; G.W. Torrance, "Social Preferences for Health Status", *Socio-Economic Planning Sciences*, 10, 3, 1976, pp. 129-136.

<sup>54</sup>See, in this connection, D.L. Patrick, J.W. Bush and M.M. Chen, *op. cit.*; A.J. Culyer, "Need, Values and Health Status Measurement", *op. cit.*; G.W. Torrance, *A Generalized Effectiveness Model for the Evaluation of Health Programs*, Hamilton, Faculty of Business, McMaster University, 1970.

<sup>55</sup>See, in this connection, D.L. Patrick, J.W. Bush and M.M. Chen, *op. cit.*; A.J. Culyer, "Need, Values and Health Status Measurement", *op. cit.*

<sup>56</sup>See, in this connection, *Ibid.*, G.W. Torrance, *A Generalized Effectiveness Model for the Evaluation of Health Programs*, *op. cit.*; G.W. Torrance, "Social Preferences for Health Status", *op. cit.*; A.D. Wolfson, *A Health Index for Ontario*, Toronto, Ministry of Treasury and Intergovernmental Affairs, 1974; I. Vertinsky and E. Wong, "Eliciting Preferences and the Construction of Indifference Maps", *Socio-Economic Planning Sciences*, 9, 1, 1975, pp. 15-24.

<sup>57</sup>See in this connection, G.W. Torrance, *A Generalized Effectiveness Model for the Evaluation of Health Programs*, *op. cit.*; A.D. Wolfson, *op. cit.*; G.W. Torrance, "Social Preferences for Health Status", *op. cit.*; A.J. Culyer, "Need, Values and Health Status Measurement", *op. cit.*



of course, that the researchers responsible for the design of these indexes did not intend to produce a sense of cardinality because they frequently group scores together into broad categories of dependence; rather the intention was perhaps to use a fairly crude system drawn up with a degree of collective agreement on some criterion, say, the importance of each item in maintaining independence, to provide a convenient means of showing the overall effects of disability, and this is why the scoring systems tend to rely on fairly uniform scores throughout one index, for instance the 0, 1 and 2 of the measure of incapacity for self-care and the 0, 5, 10 and 15 of the Maryland Disability Index).<sup>59</sup> Whatever the reason for that lack of methodological rigour, this is certainly one area in which there is scope for considerable improvement.<sup>60</sup> Some tightening up of procedures, however, is also called for in ordinal scale construction. Finally, with regard to the two substantive points made earlier, it is highly desirable that in measuring disability states we venture outside the rather narrow domain of physical and economic dependence and find a way of bringing the disabled themselves into the complex process of need identification and assessment.<sup>61</sup>

<sup>59</sup>See, in this connection, K.G. Wright, "Alternative Measures of the Output of Social Programmes", *op. cit.*

<sup>60</sup>Further methodological limitations of the indexes are discussed in: A.J. Culyer, *Need and the National Health Service*, *op. cit.*; A.J. Culyer, "Need, Values and Health Status Measurement", *op. cit.*

<sup>61</sup>The methodological aspects of this process are outlined in: C.C. Attkisson, *et al.*,



## Annexure I

### INDEX OF INDEPENDENCE IN ACTIVITIES OF DAILY LIVING

The Index of Independence in Activities of Daily Living is based on an evaluation of the functional independence or dependence of patients in bathing, dressing, going to toilet, transferring, continence, and feeding. Specific definitions of functional independence and dependence appear below the index.

- A—Independent in feeding, continence, transferring, going to toilet, dressing, and bathing.
- B—Independent in all but one of these functions.
- C—Independent in all but bathing and one additional function.
- D—Independent in all but bathing, dressing and one additional function.
- E—Independent in all but bathing, dressing, going to toilet, and one additional function.
- F—Independent in all but bathing, dressing, going to toilet, transferring, and one additional function.
- G—Dependent in all six functions.
- Other—Dependent in at least two functions, but not classifiable as C, D, E, or F.

*Independence* means without supervision, direction, or active personal assistance, except as specifically noted below. This is based on actual status and not on ability. A patient who refuses to perform a function is considered as not performing the function, even though he is deemed able.

#### *Bathing* (Sponge, Shower, or Tub)

Independent: assistance only in bathing a single part (as back or disabled extremity) or bathes self completely

Dependent: assistance in bathing more than one part of body; assistance in getting in or out of tub or does not bathe self

#### *Transfer*

Independent: moves in and out of bed independently and moves in and out of chair independently (may or may not be using mechanical supports)

Dependent: assistance in moving or out of bed and/or chair; does not perform one or more transfers

#### *Dressing*

Independent: gets clothes from closets and drawers; puts on clothes, outer garments, braces; manages fasteners; act of tying shoes is excluded

#### *Continence*

Independent: urination and defecation entirely self-controlled



Dependent: does not dress self or remains partly undressed

Dependent: partial or total incontinence in urination or defecation; partial or total control by enemas, catheters, or regulated use of urinals and/or bedpans

*Going to toilet*

Independent: gets to toilet; gets on and off toilet; arranges clothes; cleans organs of excretion; (may manage own bedpan used at night only and may or may not be using mechanical supports)

*Feeding*

Independent: gets food from plate or its equivalent into mouth; (precutting of meat and preparation of food, as buttering bread, are excluded from evaluation)

Dependent: uses bedpan or commode or receives assistance in getting to and using toilet

Dependent: assistance in act of feeding (use above); does not eat at all or parenteral feeding.

SOURCE: S. Katz, *et al.*, "Studies of Illness in the Aged", *Journal of the American Medical Association*, 185, September, 1963, p. 915.



## Annexure 2

# **EVALUATION FORM FOR THE INDEX OF INDEPENDENCE IN ACTIVITIES OF DAILY LIVING**

Name..... Date of Evaluation.....

For each area of functioning listed below, check description that applies.  
(The word "assistance" means supervision, direction of personal assistance.)

*Bathing*—either sponge bath, tub bath, or shower.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Receives no assistance (gets in and out of tub by self if tub is usual means of bathing)	Receives assistance in bathing only one part of the body (such as back or a leg)	Receives assistance in bathing more than one part of the body (or not bathed)

*Dressing*—gets clothes from closets and drawers—including underclothes,  
outer garments and using fasteners (including braces if worn)

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Gets clothes and gets completely dressed with- out assistance	Gets clothes and gets dressed without assis- tance except for assis- tance in tying shoes	Receives assistance in getting clothes or in getting dressed; or stays partly or com- pletely undressed

*Toileting*—going to the "toilet room" for bowel and urine elimination;  
cleaning self after elimination, and arranging clothes

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Goes to "toilet room", cleans self, and arranges clothes without assistance (may use object for sup- port such as cane, walker, or wheelchair and may manage night bedpan or commode, emptying same in morning)	Receives assistance in going to "toilet room" or in cleansing self or in arranging clothes after elimination or in use of night bedpan or commode	Doesn't go to room termed "toilet" for the elimination process

*Transfer*—

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Moves in and out of bed as well as in and out of chair without assistance (may be using object for support such as cane or walker)	Moves in or out of bed or chair with assistance	Doesn't get out of bed



*Continence—*

- |                                                             |                               |                                                                                             |
|-------------------------------------------------------------|-------------------------------|---------------------------------------------------------------------------------------------|
| <input type="checkbox"/>                                    | <input type="checkbox"/>      | <input type="checkbox"/>                                                                    |
| Controls urination and<br>bowel movement completely by self | Has occasional<br>“accidents” | Supervision helps keep<br>urine or bowel control;<br>catheter is used, or is<br>incontinent |

*Feeding—*

- |                               |                                                                                   |                                                                                                                 |
|-------------------------------|-----------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------|
| <input type="checkbox"/>      | <input type="checkbox"/>                                                          | <input type="checkbox"/>                                                                                        |
| Feeds self without assistance | Feeds self except for<br>getting assistance in<br>cutting meat or buttering bread | Receives assistance in<br>feeding or is fed partly<br>or completely by using<br>tubes or intravenous<br>fluids. |

SOURCE: S. Katz, *et al*, *op. cit.*





## Annexure 3

## A MEASURE OF INCAPACITY FOR SELF-CARE

Activity necessary for self-care	Score for old person's capacity to perform activity		
	Without difficulty or with slight difficulty	With moderate difficulty or only in part	Not at all or minimally
I. Mobility and personal care			
1. Get in and out of bed	0	1	2
2. (a) Bedfast, wash face and hands	0	0	2
(b) Not bedfast:			
(i) walk around room	0	1	2
(ii) leave building	0	1	2
3. Negotiate stairs	0	1	2
4. Wash	0	1	1
5. Dress	0	1	1
6. Bath	0	1	1
II. House-care			
7. Prepare meals	0	0	1
8. Clean floors	0	0	1
9. Coordinate mental faculties in performing other tasks	0	1	2
III. Communication			
10. See	0	1	2
11. Hear	0	0	1
12. Speak	0	1	2
13. Organise thoughts in lucid speech or other form for purposes of social communication	0	1	2
IV. Activities necessary to overcome special handicaps			
14. Sit or move about without fits, falls or giddiness	0	1	2
15. Control passing of urine and faeces	0	1	2
16. Manage other special (named) disabilities without help*			
— — —	0	1	2
— — —	0	1	2
Total score			

\*Where they involve restriction or prevention of activities not already listed, or where they involve the performance of special tasks.

SOURCE: P. Townsend, *The Family Life of Old People*, Harmondsworth, Penguin, 1963, p. 259.



**Annexure 4**  
**MARYLAND DISABILITY INDEX**

<i>Activity</i>	<i>Score given when activity performed</i>	
	<i>With help</i>	<i>Independently</i>
1. Feeding self	5	10
2. Coming to a sitting position on the side of bed	0	5
3. Moving from wheelchair to bed and returning	5	10
4. Doing personal toilet	0	5
5. Getting on and off toilet, etc.	5	10
6. Bathing self	0	5
7. Propelling wheelchair or walking on a level surface	10	15*
8. Ascending and descending stairs	5	10
9. Dressing and undressing	5	10
10. Controlling bowels	5	10
Controlling bladder	5	10

\*Propelling a wheelchair is not scored if walking on a level surface can be performed.

SOURCE: C.M. Wylie and B.K. White, "A Measure of Disability", *Archives of Environmental Health*, 8, June, 1964, p. 835.



## Annexure 5

### DEFINITION AND SCORING OF ACTIVITIES IN MARYLAND DISABILITY INDEX

1. *Feeding*: The patient is independent and scores ten if he can feed himself without help other than food being placed within reach. He must cut up his own food, use salt, sugar, and spread butter. He may use a straw when drinking. If he needs an assistive device, he must be able to put it on. The score is five if the food must be cut up for the patient, if he uses an assistive device which he cannot put on by himself, or if he needs help with salt, sugar, or spreading butter.

The patient scores zero if he needs more help, or if his actions are too slow.

2. *Coming to a Sitting Position on the Side of the Bed*: This activity includes getting the legs off the bed, assuming a sitting position, and moving until the body is balanced with the knees directly in front of the hips. The patient who achieves and maintains this position without help scores five. The patient who cannot reach the sitting position without help scores zero.

3. *Moving From Wheelchair to Bed and Returning*: The independent patient can approach the bed in his wheelchair, lock his brakes, lift the foot rests, get onto the bed and lie down, sit up, change the position of the chair if necessary, and return to it. He scores ten when he does these actions safely without the presence of a second person. The patient is not expected to get on and off a bed too high for his wheelchair or for his height.

The patient scores five if he performs the activity with minimal help or needs supervision for safety. He scores zero if he needs considerable help or direction.

4. *Doing Personal Toilet*: The patient scores five if he can wash his hands and face, comb his hair, brush his teeth, and shave. He may shave with any kind of razor, but must plug in an electric razor or put in a safety razor blade. Women must put on make-up, but need not care for fancy hair-dos (such as braiding).

If the patient needs help for any item, he scores zero.

5. *Getting On and Off Toilet*: The patient scores ten if he can get on and off toilet, handle his clothes, and wipe himself. He may use a bar or other support if necessary. If he cannot use a toilet, he also scores ten if he uses a bedpan, gets it into position, empties, and cleans it. The patient scores five if he performs the activity with minimal help. He scores zero if he needs considerable help.

6. *Bathing Self*: The patient may use a bath tub, shower, or take a complete sponge bath. He scores five when able to do all steps involved in the method without another person being present. The patient scores zero if he needs minimal help.



cannot walk. He scores five when he can push the chair for at least 50 yards, can go round corners, and manoeuvre the chair to a table.

*Walking on a Level Surface:* The patient scores 15 who can walk at least 50 yards without help or supervision. He may wear braces or prostheses and use crutches, canes or a walkerette, but not a walker. He must lock and unlock braces, stand up and sit down, get the mechanical aids into position for use, and dispose of them when he sits. (Putting on and taking off braces is scored under dressing.)

The score is ten if the patient needs minimal help or supervision. He scores zero if he cannot walk with minimal help or walks only in the parallel bars or in a walker.

8. *Ascending and Descending Stairs:* The patient scores ten who can go up and down at least on flight of stairs without help or supervision. He may use handrails, canes, or crutches if he needs. If he needs a cane or crutches for walking on level ground, he must carry them with him as he ascends and descends the stairs.

The score is five if the patient needs minimal help. He scores zero if he needs considerable help.

9. *Dressing and Undressing:* To score ten, the patient must put on and take off all clothes, fasten all fasteners, and tie his shoe laces. This activity includes putting on and taking off a corset or brace when prescribed. The patient may need to use special clothing, such as dresses that open down the front.

The patient scores five when he needs minimal help but can do at least half of the work himself. He scores zero when he needs considerable help. Women need not put on a brassiere or girdle unless this is prescribed.

10. *Controlling Bowels:* This activity includes ability to use a suppository or take an enema, as for paraplegic patients who have had bowel training. The patient scores ten if he does not have accidents. The score is five when occasional accidents occur, or if the patient needs minimal help in using a suppository or taking an enema. The score is zero when frequent accidents occur.

*Controlling Bladder:* The patient wearing an external device scores ten if he can put it on, clean and empty it, and stay dry day and night. He scores ten when he has no accidents.

The patient scores five if he has occasional accidents, or occasionally cannot wait for the bedpan or get to the toilet in time. If he needs help with an external device, even though he keeps dry, he scores five. The score is zero if the patient is frequently wet.



**Annexure 6**  
**SAINSBURY MEASURE OF INCAPACITY**

<i>Activities</i>	<i>Capacity to perform activity</i>		
	<i>Without difficulty</i>	<i>With difficulty but without help</i>	<i>Not at all or only with help</i>
	0	1	2
<b>I. Personal Tasks</b>			
1. Go out of doors on own			
2. Go up and down stairs			
3. Get about house on own			
4. Wash down or bath			
5. Dress and put on shoes			
6. Cut own toenails			
7. Get in and out of bed			
8. Brush and comb hair			
9. Feed self			
10. Go to toilet on own			
<b>II. Household Tasks</b>			
1. Clean floors			
2. Make a cup of tea			
3. Cook a hot meal			
4. Do the shopping			
<b>III. Physical and Mental Faculties</b>			
1. See (even with spectacles)			
2. Hear (even with hearing-aid)			
3. Speak			
4. Organise thoughts in lucid speech			
5. Sit or move without falls or giddiness			
6. Control passing of urine			
7. Control passing of faeces			
8. Manage other special disabilities without help			
9. Co-ordinate mental faculties in performing personal services			



### **Annexure 7**

### **DESCRIPTION OF DEPENDENCY CATEGORIES**

1. No impairment on any physical or mental state or self-care activity; no additional disabilities.
2. No impairment of self-care activities; no additional disabilities, mild impairment on one or two of: mobility; continence; mental state.
3. As category 1 except with 'additional' disabilities.
4. As category 2 except with 'additional' disabilities.
5. No impairment of self-care activity; mild impairment on all three of continence; mobility; mental state; with or without additional disabilities.
6. Anyone with an impairment of self-care activity who would otherwise fit into categories 1-5; anyone with a moderate impairment of mobility, including those fully capable of self-care, or with impairment of self-care activities.
7. People with a moderate impairment of mental state, but not more than mild impairment of mobility and continence; capacity for self-care not considered.
8. Persons with moderate impairment of continence, but no other impairment on any item.
9. Persons with moderate impairment of continence, any state of mobility except bedfast, any condition of mental state.
10. With moderate impairment of both mobility and mental state, but not more than mild impairment of continence.
11. Severely confused; not bedfast; not more than mild impairment of continence.
12. Not severely confused, but severely impaired on one or both of continence and mobility.
13. Severely confused with severe impairment of continence or mental state.
14. With severe impairment of all three states of continence; mobility; mental state.

SOURCE: V. Carstairs and M. Morrison, *The Elderly in Residential Care*, Edinburgh, Scottish Home and Health Department, 1971, p. 121.



## Annexure 8

### GARRAD AND BENNETT MEASURE OF DISABILITY

MOBILITY

Walking Do you walk outdoors in the street (with crutch or stick if used)?

If 'Yes': one mile or more <input type="checkbox"/>	If 'No':	and:
$\frac{1}{2}$ mile <input type="checkbox"/>	Between rooms <input checked="" type="checkbox"/>	Unaccompanied <input type="checkbox"/>
100 yds. <input checked="" type="checkbox"/>	Within room <input checked="" type="checkbox"/>	Accompanied <input checked="" type="checkbox"/>
10 yds. <input checked="" type="checkbox"/>	Unable to walk <input checked="" type="checkbox"/>	Acc. + support <input checked="" type="checkbox"/>

Stairs Do you walk up stairs?

To 1st floor or above <input type="checkbox"/>	Unacc. <input type="checkbox"/>
5-8 steps or stairs <input checked="" type="checkbox"/>	Acc. <input checked="" type="checkbox"/>
2-4 steps or stairs <input checked="" type="checkbox"/>	Acc. & Supp. <input checked="" type="checkbox"/>
1 step <input checked="" type="checkbox"/>	
mount stairs other than by walking <input checked="" type="checkbox"/>	No need to mount stairs <input type="checkbox"/>
unable to mount stairs <input checked="" type="checkbox"/>	

Do you walk down stairs?

From 1 floor to another <input type="checkbox"/>	Unacc. <input type="checkbox"/>
5-8 steps or stairs <input checked="" type="checkbox"/>	Acc. <input checked="" type="checkbox"/>
2-4 steps or stairs <input checked="" type="checkbox"/>	Acc. & Supp. <input checked="" type="checkbox"/>
1 step <input checked="" type="checkbox"/>	
goes down stairs other than by walking <input checked="" type="checkbox"/>	No need to descend stairs <input type="checkbox"/>
unable to descend stairs <input checked="" type="checkbox"/>	

Transfer

	Yes	No
Do you need help to get into bed? ... ..	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Do you need help to get out of bed? ... ..	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Bedfast ... ..	<input checked="" type="checkbox"/>	

	Yes	No
Do you need help to sit down in a chair? ...	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Do you need help to stand up from a chair? ...	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Not applicable ...		<input type="checkbox"/>



Travel	
Do you drive yourself in a car?	Do you travel by bus or train?
Normal (unadapt.) <input type="checkbox"/>	If 'Yes': If 'No':
Adapted <input type="checkbox"/>	Whenever necessary <input type="checkbox"/> Unable to use bus and train <input checked="" type="checkbox"/>
Invacar <input checked="" type="checkbox"/>	Only out of rush hour <input checked="" type="checkbox"/> Unable to use bus, train and car <input checked="" type="checkbox"/>
Self-propelled vehicle (outdoors) <input checked="" type="checkbox"/>	and:
Does not drive <input type="checkbox"/>	Unaccompanied <input type="checkbox"/> Does not travel by choice <input type="checkbox"/>
	Accompanied <input checked="" type="checkbox"/> Uses private transport by choice <input type="checkbox"/>

SELF CARE

Are you able to feed yourself:	Are you able to dress yourself completely:	Are you able to undress yourself completely:	Are you able to use the lavatory:	Are you able to wash yourself:
Without any help <input type="checkbox"/>	Without any help <input type="checkbox"/>	Without any help <input type="checkbox"/>	Without any help <input type="checkbox"/>	Without any help <input type="checkbox"/>
With specially prepared food or containers <input checked="" type="checkbox"/>	With help with fastenings <input checked="" type="checkbox"/>	With help with fastenings <input checked="" type="checkbox"/>	Receptacles without assistance <input checked="" type="checkbox"/>	With assistance for shaving, combing hair, etc. <input checked="" type="checkbox"/>
With assistance <input checked="" type="checkbox"/>	With help other than fastenings <input checked="" type="checkbox"/>	With help other than fastenings <input checked="" type="checkbox"/>	Lavatory with assistance <input checked="" type="checkbox"/>	With help for bodily washing <input checked="" type="checkbox"/>
Not at all, must be fed <input checked="" type="checkbox"/>	Does not dress <input checked="" type="checkbox"/>	Not applicable <input checked="" type="checkbox"/>	Receptacles with assistance <input checked="" type="checkbox"/>	Not at all <input checked="" type="checkbox"/>






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**DOMESTIC DUTIES** Do you do your own:

	all	part	none	preference	unable
Shopping	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Cooking	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Cleaning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Clothes washing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Men with no household duties	<input type="checkbox"/>				

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**OCCUPATION** Do you have a paid job at present?

If 'Yes':	and:	If 'No':	
Full time <input type="checkbox"/>	Normal working <input type="checkbox"/>	Male 65	{ Age retired <input type="checkbox"/> Prem. retired <input checked="" type="checkbox"/> Non-employed <input type="checkbox"/>
Part-time <input type="checkbox"/>	Modified working <input checked="" type="checkbox"/>	Female 60	
	Sheltered employment <input checked="" type="checkbox"/>	and over	
		Male 64	{ Unemployed <input type="checkbox"/> Unfit <input checked="" type="checkbox"/> Non-employed <input type="checkbox"/>
		Female 59	
		and under	

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\*Cross in any box marked with an asterisk indicates presence of disability.

SOURCE: J. Garrad and A.E. Bennett, "A Validated Interview Schedule for Use in Population Surveys of Chronic Disease and Disability", *British Journal of Preventive and Social Medicine*, 25, May 1971, pp. 99-100.



**Annexure 9**  
**HARRIS DISABILITY INDEX**

<i>Item</i>	<i>No difficulty</i>	<i>Some difficulty but can do on own</i>	<i>Not on own</i>	<i>Never does because too difficult</i>	<i>Has difficulty but not known if can do on own</i>
	(1)	(2)	(3)	(4)	(5)
1. Getting to or using WC	0	4	6	6	5
2. Doing up buttons and zips	0	4	6	6	5
3. Feeding	0	4	6	6	5
4. Having a bath or all-over wash	0	2	3	3	2
5. Washing hands and face	0	2	3	3	2
6. Putting on shoes socks/ stockings	0	2	3	3	2
7. Dressing other than buttons & shoes	0	2	3	3	2
8. Combing hair (women only)	0	2	3	3	2
9. Shaving (men only)	0	2	3	3	2
10. Getting in and out of bed	0	2	3	3	2

SOURCE: A Harris, *et al*, *Handicapped and Impaired in Great Britain*, London, Office of Population Censuses and Surveys, Her Majesty's Stationery Office, 1971, Appendix D.

## A Future for the Mentally Handicapped

Seeta Sinclair

THE MENTALLY handicapped constitute a sizable proportion of the population of India. Approximately 2 per cent of all population studied in different countries in the world are mentally handicapped, while about 4 per 1000 are severely so.<sup>1</sup> Mental handicap is defined as significantly subaverage general intellectual functioning, existing concurrently with deficits in adaptive behaviour, and manifested during the developmental period.<sup>2</sup> Intelligence is generally assessed by a number of different tests designed to measure different aspects of intellectual function, resulting in an intelligence quotient (IQ). An IQ of 70 or less is taken as mental handicap, when combined with difficulty in adaptation, *i.e.*, in the ability to meet the demands of the environment. An IQ under 50 is considered severe mental handicap for planning purposes. As these individuals will always need special services, while those in the IQ bracket of 51 to 70 are considered mildly handicapped, and some of these may be able to function adequately in an environment which is intellectually non-demanding.

The community as a whole, even the educated elite, have a very vague idea about mental handicap, usually equating it with psychiatric dysfunction where intellectual function is disturbed, as contrasted to subaverage intellect which is found in mental handicap. Most people also do not know that the mentally handicapped have potential abilities, and not just disabilities. These abilities can be developed with appropriate education and training to enable the mentally handicapped to become happy, productive and integrated members of the community, instead of being shunned, despised, ridiculed and segregated, as at present, with usually no opportunity to improve their sad destiny. The huge numbers that constitute the mentally handicapped makes such treatment of them not only inhuman but also a national waste which must be prevented. Of India's present total population of 680 millions at least 2 per cent or 13.6 million are mentally handicapped, and 4 per 1000 or 2.7 million severely so. The nation cannot afford to

<sup>1</sup>S. Sinclair, "Mental Handicap in India and Its Prevention: An Overview", In V.V. Gujral, I. Narayanan and A.K. Dutta, (eds.); *The Underprivileged Child*, Indian Acad. of Pediat., New Delhi, 1981. p. 137.

<sup>2</sup>H.J. Grossman, "Manual on Terminology and Classification in Mental Retardation", *Amer. Assocn. on Mental Deficiency*, Baltimore, Maryland, USA, 1973.



continue to add new recruits to this cohort, and to leave those affected uneducated and untrained, to burden the economy further.

### A CLEAR NATIONAL POLICY

A national policy and plan are urgently needed. A group of experts from the different disciplines concerned with mental handicap worked out a comprehensive plan, under the joint sponsorship of the Directorate-General of Health Services, the World Health Organisation, and the All-India Institute of Medical Sciences.<sup>3</sup> The various aspects covered were: national policy, prevention, medical services, education and vocational training, training of personnel providing this, employment, residential facilities, legislation, insurance, social security, committees for coordination, planning, information and advice, the roles of the individual, the community, voluntary agencies and the government and, finally, priorities for action. The salient features of the plan are presented.

India needs a clear national policy outlining the state's obligations to the mentally handicapped, and ensuring their fundamental rights—to education, vocational training and employment, to protection from exploitation, to medical care, to economic security, and to as normal a life as possible. These rights are laid down in the United Nations Declaration on the Rights of the Mentally Handicapped, and should be ratified by India.

Medical care should be geared especially to prevention, early diagnosis and treatment of all treatable conditions, primary and secondary. Education of the community, the peripheral worker such as the community health volunteer, the *anganwadi* worker, the *dai*, and all peripheral cadres of the health and social welfare services, is needed towards this end. They should be trained in prevention of mental damage, and recognition of the abnormal child, who should be referred to the nearest primary health centre (PHC) for diagnosis, treatment and advice. The PHC doctors should get orientation courses which would enable them to deal with all disability. This subject should also be stressed in the medical curriculum. Emphasis should be on adequate medical services available as near the home of the disabled as possible. Only those who cannot be adequately diagnosed or treated at the PHC level should be referred to the district hospital, and finally to the medical college if necessary. Multipurpose therapists should be available peripherally, either posted at the PHC, or as part of regular visiting teams, going out from the district hospital or the medical colleges. They should be trained in physiotherapy, occupational and speech therapy. Training of such workers should be a priority in planning.

<sup>3</sup>S. Sinclair, *National Planning for the Mentally Handicapped*, Mehta Offset Works, New Delhi, 1979.



## COMMUNITY EDUCATION

Prevention should stress adequate supervision of deliveries, as birth trauma and anoxia are responsible for approximately 25 per cent of all cases of mental handicap. Education of the community regarding the risks of consanguineous marriages, family planning to ensure birth of children between the relatively safe maternal ages of 20 to 30 years, adequate ante-natal care of the pregnant mother, medical termination of pregnancy if there is reason to believe that the fetus is abnormal, follow up of high risk pregnancies, adequate care of the infant and pre-school child, with early immunization and sanitation to protect against disease, and early treatment if disease occurs, were other preventive measures recommended. All this is feasible with strengthening of the health services, and emphasis on education of the peripheral worker and the community. Administrative details were also worked out.

Educational services recommended were emphasis on day schools and day care centres to be started widely. The integrated education scheme of the Central Ministry of Social Welfare provides for disabled children to be taught in schools for normally intellectually endowed children, where a special teacher will be employed for every 10 handicapped children.<sup>4</sup> Academic subjects would be taught separately to such children by their teacher, using any special materials needed. Such a 'resource' teacher and 'resource' materials would be subsidised by the Central Government, as well as the fees and transport of affected children, to a large extent. In subjects like games, drill, art, drama, music, recreational activities and meals, the handicapped would join the non-handicapped children. Wide publicity should be given to this scheme, as it can ensure education to most mildly handicapped children, who form the majority of the affected population.

Residential schools and homes are not advisable, as the care is generally poor, the children are segregated from normal life and from their families and feel rejected, and opportunity for development is poor. However, one good residential-cum-educational institute should be provided for each large city, for those who cannot be cared for at home. Residential facilities for the adult handicapped were recommended.

Vocational training centres with attached sheltered workshops should be started widely. These should teach a variety of useful economically viable trades.

Emphasis should be placed on development of the handicapped to as much independence—financial, social, and residential—as possible.

Training of teachers and vocational trainers must take a high priority

<sup>4</sup>Department of Social Welfare, Ministry of Education and Social Welfare, Government of India, *Scheme for the Integrated Education for Handicapped Children*, Printing Press, Institute for the Deaf, New Delhi, 1975.



in any plan for the handicapped. This was worked out in some detail. Adequate, university recognised courses are needed. Immediate absorption of the graduates of such courses in suitable jobs and at suitable salary scales was recommended.

Early home based services and home stimulation programmes with parental involvement and counselling services were recommended.

Diagnostic and evaluation services should be provided by a multi-disciplinary team.

Employment of the mentally handicapped is a much neglected field. Sheltered workshops and farms, open employment, contracts with industry, reservation of some types of work, special employment exchanges, preferential purchase by government of products made by the handicapped, incentives such as income tax exemptions to employers of the handicapped, and training in rural occupations given by village artisans and others, for those in rural areas, were some of the measures recommended.

Legislation to protect the rights of the handicapped is an essential priority.

Insurance schemes need to be worked out to provide economic and social security to the handicapped. The schemes currently offered by the Life Insurance Corporation of India are not very useful.

Central institutes for mental handicap, preferably regional, are needed for coordinating services, planning and execution of plans, acting as referral bodies, and as repositories and disseminators of information on matters concerning mental handicap and all facilities for the handicapped, for indicating priorities in services, research, etc., and for advice on all matters connected with handicap, to the community, individuals, government and voluntary agencies.

Coordination committees should be set up at central, middle and peripheral levels to undertake much of the work indicated above, and for liaison.

The community must be included in all programmes. The media should be involved.

Priorities for research, relevant to conditions in India, were considered and specified. Monitoring and evaluation of all service programmes is essential research, and should be incorporated into all service programmes, as an integral part of these. Focus on studies of prevention of handicap, of coping of the handicapped with different environments and social conditions, and of their adequacy and productivity in different types of employment, was suggested.

#### PARENT SELF-HELP ASSOCIATIONS

It is fervently hoped that this national plan will be implemented even if partially, and not be fated to gather dust on the shelves of archives and store rooms, which is the usual fate of plans and reports. Recently, parent



self-help associations are being formed in different parts of India. These can do a great deal to implement the suggestions incorporated in the plan. The impetus given to such work by the International Year for Disabled Persons should not be allowed to die away. Enthusiasm, optimism and willingness to work and take responsibility are needed if we really want any improvement in the lives of the handicapped.



## **The Growing Needs of the Aged Disabled: Some Considerations**

**Thomas D. Watts**

**T**HE AGED disabled are examined in this paper as a sub-group of a larger population (the aged) with particular needs. The focus of this paper is on the aged disabled in the United States, with some comparisons made to India, and to other countries. It is argued here that the fate of the aged disabled is tied to: (1) A societal commitment of equality, (2) economic growth, and (3) a willingness on the part of governments and societies to focus on the specific needs of the aged disabled. This paper does not closely study the mechanics of policies directed towards the aged disabled in the US and India. The difference between the U.S. and India in these and other areas is considerable, and it is not presumed that the experience of either country is applicable to the other. This paper, instead, focuses on three considerations that the US, India, and all countries must in some way discuss and resolve in respect to the aged disabled. Indeed, the fate of the aged disabled to a large extent is dependent on how these three considerations are treated and resolved.

The definition of terms such as 'aged' is, of course, dependent on the social and cultural context of any society, and beyond this the theological and philosophical views of the definer. The President of the United States, Mr. Ronald Reagan, is in his seventies and is in one sense 'aged' (if we define the 'aged' as being over age 65, or age 60, as many do). A black or Afro-American older woman living in poverty in the United States, assuming that she has reached a comparable age (seventies) lives in a very different social and economic milieu, and may look at herself and aging much differently. Certainly, this state of life (being aged) is looked at differently in India, in China, in West Germany, in Brazil, and throughout the world (cf. Fry. 1981). The term 'aging' refers to the "various biological, psychological, and social processes that result in relatively predictable changes in mature humans as they advance in chronological age". (Atchley, 1980:5). *The American Heritage Dictionary of the English Language* (1969:24) lists several definitions of 'age' one of which is: "The period of time during which someone or something exists." In this sense, the 'aged' exist at a given point in time that differs appreciably from that of the young child. Still, both the 'aged' and the young child participate in the 'aging' process.





## THE AGED IN THE UNITED STATES

The aged in the United States are growing more rapidly than any other age group within the population. The aged (over age 65: I will use age 65 unless stated otherwise in this paper) increased in size from 4.9 million in 1900 to nearly seven times that number in 1977 (32.8 million) (U.S. Dept. of Health, Education and Welfare, 1978: 2-4). The aged population in India (70+ years) is expected to increase from 9.9 million in 1971 to 19.1 million in 1991 (Parthasarathy, 1980: 383). This is happening all over the world, as a United Nations study underscored (1975).

Within the aged population as a whole, there are many aged who are in good physical condition, often in better condition than younger people. However, it can be said that the more aged suffer from more disabilities, minor and major, than other segments of the population. Eighty-six per cent of the 65 and over population of the United States (15.4 million persons) are estimated to have one or more chronic disorders, and 25 per cent of the medical costs in the United States are accounted for by older persons (who comprise about 10 per cent of the total population) (Morgan, 1979: 26).

Defining the 'aged disabled' is as onerous a task as defining the 'aged'. Indeed, terms like the 'disabled' are at least as culturally anchored as is a term like the 'aged'. A disability that might be considered relatively major by a middle income aged person in America might not be considered so by an aged person in rural Bangladesh. Philosophical and religious views, combined with cultural factors, personal values, and other aspects, strongly influence the way that disability is looked at and experienced. 'Disability' is a 'disabled state or condition; incapacity.' By 'disable' we mean to 'weaken or destroy the normal physical or mental abilities of; to cripple; incapacitate' (*The American Heritage Dictionary of the English Language*, 1969: 374). Disability can take on physical or mental forms. Assuredly the aged person who suffers from chronic, severe depression but is otherwise in relatively good physical condition might be considered as 'disabled' as a wheelchair-bound aged person with many physical complaints and problems. It might also be helpful to distinguish between being a person with a disability on the one hand and being a disabled person on the other. Many aged are persons with disabilities, but are continuing to work and are not 'disabled persons' as such.

The human organism gradually diminishes in function over time. On the average, a person of 75 compared to himself or herself at age 30 will have 92 per cent of former brain weight, 84 per cent of basal metabolism rate, 70 per cent of kidney filtration weight, and 43 per cent of maximum breathing capacity (Leaf, 1973: 52). These losses of functions and capacities vary with individuals. Diseases afflict some aged persons more than others. But certainly aging, disabilities and also death are inevitable in the human



species. Modern medicine, despite many technological advances, has not changed some basic realities such as these.

With the increase in the aged population has come an increase in the aged disabled population. The 75+ aged in America (sometimes referred to as the 'old-old' while the 60-75 age group is in the 'young-old' category) is the fastest growing segment of the aged population (Lowy, 1980:26). The 75+ aged are the segment of the aged population with the most disabilities. They are the major users of services other than socialisation/recreation services, as Kahn and Kamerman noted in their study of social services in eight countries (US, Canada, United Kingdom, France, Federal Republic of Germany, Poland, Yugoslavia, and Israel) (Kahn and Kamerman, 1980: 303). This is true as well in countries like India, where it has been estimated that approximately 5 per cent to 8 per cent of the aged are invalid and in need of a helper (Desai and Bhalla, 1978). In India, as the aged population grows, so the aged disabled population grows, and so too does the need to attend to these seminal problems.

#### GOVERNMENT COMMITMENTS TO EQUALITARIAN GOALS

The growing aged disabled population, worldwide, presents a real challenge to government policies, and indeed to the overall commitment of governments to equalitarian goals. Certainly 'equality' is one of the most ambiguous words in the language, which is paradoxical in view of the fact that it implies perfect precision (Gordon, 1980: 99). A stated commitment to equalitarian goals then is in many ways a relatively easy thing for a government to do, but much more difficult is it to follow through with performance. Communist governments claim a kind of hegemony on equalitarianism, yet performance seems to fall short of reaching these lofty goals (Parkin, 1971; Djilas, 1957). Contemporary 'welfare states' are less vocal about equalitarian goals, but still do claim varying kinds of commitments in these areas. Examples of contemporary 'welfare states' would include Sweden and the United Kingdom, and might include the United States as well (Morris, 1979) but to a lesser degree.

The modern concept of a 'welfare state' presupposes a "minimum economic standard wherewithal for maintaining man's physical well-being and a comprehensive network of protective and constructive services in the social field such as public health, medical care, labour welfare, social welfare and social education" (Madan, 1969: 4-5). India has proclaimed welfare state goals in its constitution which are quite laudatory. A problem for countries like India (and other countries as well) is implementing these goals with the scarce resources available (Lamb, 1975: 232) and within the context of the tremendous variety of India's languages, cultures, religions, peoples (Sopher, 1980). Increasingly, this is a problem as well for 'welfare states' in the west such as the United Kingdom and the United



States, who have had many more economic and material resources upon which to draw. This is our next point of discussion, but once again it needs to be stated that the fate of the aged disabled does rest firstly on a commitment by governments and societies to equalitarian goals. "There is a new quest for a world of peace and justice in the public pronouncements of all leaders and thinkers of our time, though there is no concentrated action to achieve it (Osthathios, 1980: 15). Data would appear to indicate that "the rich are hardly being squeezed to the wall by the welfare state" (Wilensky, 1975: 90). Both pronouncements and firm actions towards equalitarian goals must conjoin in order for the aged and the aged disabled to obtain the kind of life in old age that they so richly deserve.

Equalitarian goals must be accompanied by economic growth. De Jouvenel (1954) has noted that intellectuals are prone to take an attitude of moral superiority towards people in the business world. This might be understandable of intellectuals or others on the political left. But not so understandable in the curious inability on the part of many to see the necessary connection between the welfare state and economic growth. To put the matter rather baldly, welfare state services must be paid for by the grit of economic growth. Social services cost money. The kinds of social services called for in the modern welfare state cost a great deal of money, and time, and forethought. Often within the temporary welfare state schema the "obligation to work is perceived as roughly on a par with the obligation to pay taxes" (Jordan, 1976: 192). In the sense in which I am speaking, an invention by an enterprising inventor that contributes to an increase in some way in the gross national product of a given welfare state country in turn contributes to the funding of social services. Without a requisite amount of economic growth, public expenditures for social services are difficult if not virtually impossible. Haiti, Peru and other desperately poor countries are examples here. For real economic growth to occur in these countries major changes in the way power is exercised must take place (Brown, 1974: 225). The relationship between dependence and underdevelopment is a striking one (Cockcroft, Frank, Johnson, 1972) and too involved to consider in detail here. But the issue should be clear: the relationship between economic growth and developed welfare state services is pronounced.

Welfare states in the western, industrialised countries, with all the resources at their disposal, are finding it increasingly difficult to support the growing number of dependent populations in their midst. Certainly the size of military expenditures (Sivard, 1980) lessens the ability of countries to contribute to social expenditures. Countries like India face many of the same problems: social problems beg for solution, social services are much needed in many areas, and the needs do not diminish but grow. Governments are strained to the breaking point to meet those many needs. Within this context, it still must be asserted that economic growth must take place in order that social policies might be formulated and implemented.



### CUT IN SOCIAL WELFARE SCHEMES

In the United States at the present time there appears to be a somewhat prevalent political mood to curb what is perceived by many to be a 'ward' welfare state (Freeman, 1981). As such it is instructive to view the aged disabled and the aged within that context (heretofore the recipients of the most sympathetic attitudes in respect to welfare state expenditures) (Hudson, 1980: 156). Political conservatives argue that economic growth and combating inflation is paramount, while those of more liberal persuasion place more stress on meeting human needs through various kinds of social programmes. But both may be right. Welfare state services to the aged disabled can only be supported by a requisite amount of economic growth. Economic growth will only falter in the long run unless the major social problems of a society are addressed.

A third factor in this equation in respect to the aged disabled is the need for a willingness on the part of governments and societies to focus on the specific needs of the aged disabled. In a study of the social policies of seven countries towards the aged sick (United States, Canada, the Netherlands, Denmark, Norway, France and Belgium), Gommers, Hankenne and Rogowski (1979: 136) found the following points in common: (1) A realisation of the extent and degree of the problems of the elderly has been brought about by their increasing numbers; (2) Social legislation and geriatric projects are all of relatively recent date and are therefore still at an experimental stage; (3) There is a need to correct mistakes due to a traditional approach; (4) An obvious disparity exists between estimated needs and the institutions and services available; (5) Institutionalisation is no longer seen as the unique solution to the problems of the elderly.

The aged disabled are hampered in respect to being vocal advocates of their cause by being both aged and disabled. A bedridden aged disabled person finds it much more difficult to contact politicians, to wield influence, even in comparison to non-disabled aged. Still, in American society, their numbers and their voices are heard with greater frequency. The growth in the number of the aged as a whole, and in the number of the aged disabled, has already been reiterated.

This leads us to a singular point: Welfare state countries are now and will in the future find it increasingly difficult to attend to all the needs of their aged citizens. West Germany, for example, faces a problem confronting many societies, namely, how to support an increasing aged population through the increased productivity of the younger segment of its population (Lowy, 1979: 225-226). Countries like the United States have in effect turned to the well aged for assistance in funding the social security programme by legislatively encouraging a lengthened stay in the work force. Unfortunately, social policies in America focus less on some of the causes of increasing health costs for the aged, such as a system that makes the



provision of health services increasingly profitable to the private enterprise health industry (Ehrenreich and Ehrenreich, 1970), and more on who or how such costs are to be borne (or not to be borne): through welfare expenditures or by the aged disabled themselves.

An understanding within the Indian context of the cultural traditions and the total historical context of Indian society is seminal in respect to social change (Chekki, 1978: 177). Desai and Khetani (1969:111) assert that in India the "noninstitutional services using the family as a base and emphasising mutuality to help and benefit should be encouraged, because of the nature of traditional Indian society". This same approximate recommendation could as well be made in American society or throughout the world. There would appear to be a growing consensus among many in the gerontological community, and as well in many countries throughout the world, that nursing home institutions, or institutions of any kind should be used as only a last option. Certainly there are many non-institutional approaches to the care of the aged disabled that are not only more humane but in general less expensive.

#### INSTITUTIONAL OR HOME CARE?

Still, institutional care in the form of hospitals, nursing homes, etc., will still be needed in respect to the aged disabled. Vatuk (1980) has examined the commonly held assumption that there is no real need for the provision of services for the elderly in India outside the family setting. Yet the number of old age homes in India providing care for the destitute poor is inadequate and many have poorly paid and limited staff (Desai and Khetani, 1969: 112). Nursing homes in the United States are uneven in quality, and many of the aged in them do not need to be there. Nursing home care in the United States, unlike most European countries, is a profit-making enterprise (Kane and Kane, 1978). Many in the United States are of the opinion that institutional care has been stressed too much and in-home care too little (for example, home health services represent only about 2 per cent of medicaid long-term care expenditures) (Estes, 1979: 106).

The aged disabled need special attention within aging policies in India, in the United States, and throughout the world. More aged citizens who are not disabled will have to shoulder more of the economic load. More importantly, policies that emphasise income parity must be pursued. In the United States, as in many other countries, some have inordinately high incomes while others live in abject poverty. It would hardly be fair to approach the problems of the aged disabled in other than equalitarian oriented ways. Finally, as has been discussed, the economic productivity of socialist, welfare state and other societies is intimately conjoined with the ability of societies to provide social services to its aged disabled citizens. Hence, social justice, equalitarianism and economic productivity go together. India is



attempting to move in some of these directions with its Sixth Plan for 1978-83. "With its large allocations to agriculture, to small-scale and cottage industries and to social services," states Agrawal (1978:6), it seems to direct a big chunk of resources to the neglected sectors of the economy and the weaker sections of the population." The question here is whether there still is too little spread out too thinly. This is occurring at the same time that the United States is pulling back on its social services, and putting full weight behind encouraging economic (and military) growth. The aged disabled in both India and the United States stand relatively mute while politicians and decision makers make decisions that ultimately determine their fate. These decisions are increasingly being couched in both countries within the context of scarcity and declining resources, a phenomenon of our times that both rich and poor countries will increasingly experience and share, and hopefully not to the detriment of the aged disabled in their midst, who assuredly deserve the most that societies can provide for them toward their overall wellbeing and happiness.

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## **Disability is Not a Handicap: A Positive Philosophy for the Development of the Disabled**

**Afzal Jehan Friese**

**T**HERE IS a general belief that the measure of a society's enlightenment is the quality of care and concern it shows towards its disabled. Off-hand, one could hazard the remark that we Indians manifest great concern and provide warm care as individuals to those within our immediate and extended families, but show scant concern about those not in our immediate purview. Witness the deaf, the halt and the blind who throng our streets and places of worship, the most distressing being young, crippled or maimed children, who appear sound of mind if not of body.

Are these signs of a public apathy, a deep malaise in society at large, individual philosophies of "live and let die for I am not my brother's keeper"?

Perhaps, a little of all these elements obtain but the larger contributing factor is the lack of a well-defined philosophy, and therefore of policy, vis-a-vis the disabled. We do not have an understanding about the needs of the disabled, the nature and implication of their disability to themselves, to their families and ultimately their communities and the nation. It is, however, puzzling that though the existence of disability is not a new phenomenon, a valuable philosophy and policy about it is not present today. Perhaps, drastic and rapid change in sociological structures, due to historical developments and technological advances are responsible. The older philosophy, viable and appropriate at one time, is not so today.

### **THE ROLE OF THE FAMILY**

Traditionally the deviant individual, deviant because of disability or delinquency, was accommodated by the large Indian family. A role was found for the individual and a definite identity was established. Skills necessary for living within the family were taught and learnt, they being well within the ability of the family to teach. I refer to such skills as are necessary for communication, self-care and simple occupations.

We can still see this system at work in quiet rural settings where time is not of much consequence. People's needs and expectations are simple and





great sophistication is not required. For example, in a little village in Tehri Garhwal, the only disabled person is an elderly woman who lost her sight when the corneas were damaged after her eyes were rubbed with sacred ash in an attempt to cure conjunctivitis. This woman manages her small farm, walks about the village with the aid of a stick, does her housework, cuts and sews and looks after her grandchildren. She has an occupation, shelter, companionship and is highly valued as she is considered the best cutter in the village.

In a village in Haryana, the local school has a young crippled boy with contorted and atrophied legs who hops about at great speed. He seems well-adjusted, performs satisfactorily at school, has friends and helps at home. Undoubtedly his job options in the future will be limited but in his relatively non-demanding and accepting environment he will be able to cope.

In contrast, urban areas put great strains on these coping mechanisms. Technological advances, such as fast motorised transport, high rise buildings and the many machines and contraptions useful to the normal person constitute added difficulties to the disabled. The faster pace of life and the urgent need for money force entire families to go to work leaving little time to care for their young. The impersonality of life also takes its toll. For the intelligent and sensitive disabled individual, urban life must often appear a hopeless obstacle race.

For the less affluent families in urban areas, a disabled child is an added financial, physical and emotional burden. This is particularly so if the disability is severe and intellectual. There is no time to teach the child necessary skills, and available facilities for training and education are few, and beyond their means. Transportation is difficult. Relief from constantly having to look after the disabled individual, by offers of help from friendly neighbours, is not easily forthcoming. The future looks menacing in terms of employment and care for the child. There is anguish for affluent families too. The family finds it difficult to accept a less able child, who will not in all probability fulfil family expectations. Advice is rarely forthcoming on how to help the child adjust to life and cope with his handicap. Counselling services are few and inadequate. As with the less affluent, the problem of providing for the child after the parents' death looms large.

Given the stresses and demands of city life, the parents of disabled children whether affluent or otherwise feel put upon, ashamed, inadequate and unable to cope. The child tends to feel insecure, have a poor self-image and so to develop maladaptive behaviour patterns.

#### THE COMMUNITY'S RESPONSE

What is the community's response to this? Judging from articles in the press and from statements made by those in positions of influence the



panacea is 'love and dedication'. No mention is ever made of professional skills and competence, of a need to understand the nature and demands of disabilities, of educational needs, of aptitudes and desired attitudes for occupation, of skills for living within the home and the community, or efforts to inform and educate the community and of the worthwhile contributions the community could make. Nor is much demanded of the disabled individual either. The demand is to reserve jobs for the disabled and to wheedle employers into employing them. Where is the attitude that says the disabled must also be competent? Is a sterile pity enough? Surely not; the disabled who do acquire marketable skills know that they must be better and more hardworking and productive than their normal peers if they are to retain their jobs. They frequently push themselves at the cost of their mental health and that of their families. Their employers either have no idea of, or have scant concern for, the strains the disabled employee endures.

Further misconceptions of the disabled are the myths that abound. The blind, it is felt, should have jobs as music teachers or as cane workers. The deaf are supposed to be marvellous at mime and photography and these are the professions talked about. And nobody ever bothers about the mentally deficient. Has anybody tried to find out what jobs disabled individuals aspire to and could be qualified and educated for? Who knows how many would-be gifted technicians, engineers, lawyers, accountants, etc., have been denied opportunity because of their disability? Perhaps, many mentally retarded individuals could have been educated and taught to work with the sick and with young children; they certainly have the perseverance, patience and warmth and affection required. But appropriate skills, attitudes and behaviour have to be taught. How many of the schools that exist have the teaching of such skills within their curricula?

In some countries other than India, people with disabilities show remarkable achievements. The blind with an academic bent of mind have become lawyers, even judges, social workers, etc. Those not so inclined manage news-stands and gift shops. Physically disabled persons are employed in all walks of life, the limitations imposed by their disability being compensated for by prostheses and modifications in their physical environment. Mentally retarded persons work independently and productively on farms.

#### SOCIAL COST OF THE DISABLED

Obviously then, achievements by the disabled are not dependent on the disability, but on the opportunities provided for learning and development of skills and desired attitudes. It is a lack of the necessary inputs which makes the disabled a social burden. It is fallacious to argue that specialised and large expenditure on the disabled for purposes of education prostheses and training is extravagant. Denial of the services this money could buy is enormously wasteful to the nation, because it is not just the disabled but



their families who are economically less efficient. Social costs are even greater.

Indian efforts should be directed towards making the disabled as independent as possible. The plans for integrated schooling are a step in the right direction but only if personnel are available with the necessary skills for teaching such classes. Diagnosticians, counsellors and other properly oriented professionals are also required. A first step would be to educate and prepare such personnel at our universities.

Liaison should be established with would-be employers in business, industry and other professions to help and advise on the possibilities of placement. Efforts in rural areas should be directed not at labelling and displacing disabled individuals, but in providing the necessary inputs—financial, educational, technical and remedial—within the community where the disabled are located. Resource centres of information, personnel and equipment can be gradually started at district level. Scholarships such as those provided by the talent search contest can be given after similar testing and evaluation to the disabled from rural areas with the requisite capabilities, aptitudes and attitude for further studies.

Better run residential units—to some extent such units will always be required—which are run on the basis of the greater part of the management being undertaken by the residents will indeed provide a home away from home. Another approach could be to start schemes of placing children with foster families supported by state subsidies.

Even with the limited resources at our disposal, there is a great deal which can be done, provided all our programmes flow from a consistent and constructive philosophy. The most important thing to bear in mind is that the disabled person is not looked upon as a burden, an unfortunate being and an object of pity. With the proper attention and care, the disabled too can be helped to realise their full potential, making them into assets for themselves, their families and the nation.



## Planning for the Rehabilitation of the Disabled

S.D. Gokhale

IN A small lane located next to our office, there is a row of professional pavement barbers. One of them, Raju, is disabled but, what is worse, he is an 'immigrant' to Bombay twice over. (The first time was when he had visited Bombay to get his disability treated. The second time was to move here permanently). When we asked him why he felt compelled to move to Bombay, rather than continue to stay on in his village after he was supplied with an appliance and technically declared rehabilitated, he replied that the wheelchair provided to him after his accident had made it impossible for him to continue with the barber's profession in his native village. Evidently, since he had to resort to the use of a table and chair, most of his clients in the village did not view his new style of functioning benignly. His status and caste in the rural community did not really permit him the luxury of serving his clients seated in a chair. He had, therefore, in desperation, sought shelter in the city where, fortunately, he was able to build up a steady clientele despite having to use a chair.

This is just one poignant but potent illustration of how rehabilitation, *unless it is closely related or attuned to the total environment of the disabled person*, can restore functionality only very superficially. It is also a pointer to the fact that an appliance is only a *tool* to restore a lost function, it is *not* the function itself. For the appliance to serve truly as a function, much depends on the social values and social relationships obtaining around the disabled person.

There are a number of other examples to demonstrate the futility of a piece-meal approach. Take the case of a farm labourer who has his leg amputated and discovers that the artificial leg provided to him is of little use in the paddy fields where he has to stand in mud and work for the whole day. For that farmer, the use of a hand-made bamboo or wooden stump or a pegleg is not only more convenient but infinitely cheaper. It is more easily repairable as well as replaceable. Finally, it is the most effective way in which to indigenise the appliance and the rehabilitation care rendered to the disabled farmer making both more responsive to the raw materials and production skills locally available.

In this case what is demonstrated is a clear need for application of appropriate technology to rehabilitation in the rural setting.



## THE PROBLEM

While examples of these limited approaches to rehabilitation are observed both in developed and developing countries, as also in urban and rural sectors, my feeling is that they are most *acutely* manifested in the *rural* areas. Rehabilitation efforts in the rural sector are grossly prejudiced not only by a simple arithmetical lack of adequate detection, prevention and treatment but also by insufficient appreciation of the need to treat functionality and its restoration in a *total, societal* rather than in a *purely physical* context.

The genesis of the problem lies in the fact that rehabilitation as an area of national concern has traditionally been a lower priority with planners whether in government or outside. One of the clearest indications of neglect of disability is the inability of the national planners to assess the real magnitude of the problem itself especially as it occurs in rural areas. What is the extent of disability, and what and where is its manifestation, etc., are not known to planners, especially in developing countries.<sup>1</sup> In India, for instance, the decennial census has not succeeded in enumerating the population of the handicapped. However, an attempt is made to assess this problem in the 1981 census. If we take into account the WHO estimates, as much as 10 per cent of the population of most countries, particularly developing countries, is to be taken as handicapped. Applying this criteria, the handicapped population in India would be around 68 million.

Whatever the precise figure, what is worth noting is that the incidence of the handicapped population in rural India is *twice* that in urban India. This establishes that the major disability problem exists in rural areas. Yet, and notwithstanding that, rehabilitation services, following the pattern of other social services (such as health, education, nutritional care, housing, etc.) have concentrated mainly on tackling the disability problem in the urban areas.<sup>2</sup> This has meant a two-fold neglect of the handicapped in the rural sector; not only is the incidence there more but the coverage by the rehabilitation services of the rural population is substantially less, if not totally

<sup>1</sup>In my opinion, however, this is only a superficial problem, the significance of which is overlooked by planners or others who are more interested in begging the issue than in coping with it. Effective planning and programming of medical and other rehabilitation, I feel, need not await a more scientific or precise knowledge of its incidence, nature, etc. The magnitude of the existing problem is in any case acute enough to warrant immediate as well as systematic attention. Somewhat similar to this was Gandhiji's sceptical attitude towards measurement of poverty. (He used to contend that where there is an ocean of poverty, one need not bother to measure its depth prior to taking corrective action).

<sup>2</sup>In India, for instance, national institutes dealing with one or the other disability type (*viz.*, blindness, deafness, etc.) are all located in urban areas. Medical as well as vocational rehabilitation services are also mainly in cities.



lacking.<sup>3</sup>

Planning for rehabilitation in the rural sector, atleast in a country like India, has therefore to address itself to a correction of precisely this lacuna—namely, of a higher degree of incidence and a lower level of rehabilitation care in the rural sector.

Another essential perspective is that the core disability problem in rural areas is not only in *quantitative* but also in *qualitative* terms. The type of disability in rural areas is vastly different from that prevailing in the urban. Road and industrial accidents, environmental hazards, etc., may create a different disabling syndrome than domestic fires, farming accidents ill-informed use of agro-chemicals, consumption of adulterated food or drink, etc. Then again, genetic disability acquired as a result of pre-natal and post-natal nutritional care is far more in the rural sector.

Since the causative syndrome of rural disability is different, it naturally calls for the requisite specialised approaches in rehabilitation covering all its basic component areas, *viz.*, prevention, detection, diagnosis, correction (covering medical and technological care), restoration, and socio-economic rehabilitation. It should also be borne in mind that rehabilitation services should be planned to meet the assessed needs of a nation, not patterns or requirements transposed from other nations or areas. The service pattern should be tailored to fit the assessed needs of each area within the nation, *e.g.*, while vocational rehabilitation in an urban area may lead to a marketable skill, in rural non-monetised economy, it may more profitably be directed towards acquisition of usable skills for personal autonomy and independence.

### THE HISTORICAL PROCESS

Some of the onus for causing the piece-meal approach to rehabilitation must lie with the evolutionary process itself, especially as it concerns the creation and operation of services in other social sectors, namely, health, education, housing, employment, etc. All these services began initially as specific 'aids' to the individual. It is only later, when they expanded, that they gradually became a 'system', or fullfledged 'community' services. This evolution, however, has not yet overtaken the field of rehabilitation where the treatment or correction of disability continues to be viewed as an aid to the individual given with the limited object of restoring his functionality to the maximum possible level, rather than a total service rendered to the individual and impinging on his social relationships, economic capacities, and environment all of which bear significantly on his rehabilitation.

<sup>3</sup>Absence of adequate rehabilitation facilities, it must be conceded may also be due to administrative and other difficulties posed by remoteness of the region, difficult terrain, etc.



## THE INTERNATIONAL ASSISTANCE

International cooperation and assistance that we have been receiving have produced some islands of excellence—centres, schools and programmes as well as the models, from which they have been devised. But the totality of the existing services reaches very few people. We may, therefore, question whether the concept of rehabilitation services that has evolved in the industrialised west is necessarily appropriate for areas with quite a different economic and social ethos. What we need, therefore, is the model of 'rehabilitation service' to suit the Indian condition.

It was assumed in the western model that, by stimulating and assisting the establishment of show-place institutions in capital cities, we would start a percolating process that would eventually diffuse appropriate levels of service to the smaller communities. When we talk about national programmes, we refer to the network of show-place centres, which would percolate. This has not happened and we should now know that it will not happen unless there is a very hard headed plan.

A high priority must be given to convince everyone who deals in policy that disability is an important cause and consequence of underdevelopment and that dealing with it must be a priority item in any intelligent development plan.

The most important asset for any programme for disability prevention and rehabilitation is the family, and in most developing areas the ties and functions of the family are strong components of the social context of the individual. Successful work at this level, by remaining within the family and the existing social framework of the individual's life, can do much to maintain normal human development, whether or not the impairment can be eliminated or reduced.

## COMPONENTS OF PLANNING

It is evident that rehabilitation planning, particularly for the rural sector, pertains to transforming rehabilitation from an individual 'aide' to a community 'service' which must be hastened since that is the principal way in which to overcome the gap created by the absence of even minimal conventional services.

A sequel component to the above would be to ensure adequate inter-sectoral (both cross sectoral and intra-sectoral) linkages. The useful linkages as have been drawn between paediatrics and public health, between health and nutrition, and between all those and education are not yet reflected in rehabilitation. Nor are preventive or public education elements given appropriate attention as complementaries to rehabilitation. Only the broadest possible approach that is able to meaningfully reflect such reinforcing links will be helpful in putting the limited servicing resources, available to a





developing country, to optimum use. It would also enable disability to be treated in its totality, rather than in isolation.

A third component would be to redress the present imbalance between rural-dominated need and urban-dominated service. This means reversal of priorities not only in planning and budgeting but also in the evolution of the service itself. At present, the phenomenon common to all social sectors is that there is a wide gap between the two ends to the service spectrum. In the cities and metropolitan areas, the very best and costliest facilities exist for rendering care. At the other end are remote rural areas, tribal areas, or other backward regions where the service is either non-existent or is terribly sparse. While such service imbalances can be contended with by the normal population, for the disabled, the difficulties in commuting and gaining access to distant services are immense. In their case, the adage of 'reaching the service to the people' becomes much more than a slogan.

#### DEFINITIONS

Before outlining the problem and characteristics inherent in the rural sector, it is necessary to establish definitional clarity. Rehabilitation refers to "the combined and coordinated use of medical, social, educational and vocational measures for training or retraining the individual to the highest possible level of functional ability". (WHO, 1969 Expert Committee on Medical Rehabilitation TRS No. 419). However, this is only a partial view of rehabilitation, since, it "relates mainly to interventions aimed at the individual and neglects those aimed at changing the factors in his immediate surroundings or in society at large. This definition also excludes preventive and curative measures which are important to reduce the disability problem". (WHO, A 29/INF. DOC/1, 28th April, 1976, p. 13).

A broader view of rehabilitation as a process restoring total functionality to the disabled individual is thus called for. The concept of rehabilitation is recently viewed from different angles. In general, it could be said that rehabilitation falls into four major interlocking phases, viz.,

- physical rehabilitation;
- vocational rehabilitation; and
- psychological rehabilitation.

Rehabilitation should aim to rectify the adverse effects of disability as far as income and work are concerned, notably by:

- restoration of the disabled person to a useful role in the work force, thereby ensuring an income for him or her and his or her household and contributing to community and national development.





- raising the low social status of the disabled individual, improving in particular social relationships with colleagues and employers.
- integration or re-integration of the disabled in the community.
- mobilisation of people in the community to become involved in rehabilitation effort; such communal involvement may help to produce a healthier society and promote the general well being of all of its members, particularly by increasing their capacity to accept and deal with disability.

### RURAL VERSUS URBAN

Applying the above broad definition to rehabilitation naturally throws up several areas of disparity between rural and urban rehabilitation. These can be viewed as direct consequences of the peculiar milieu obtaining in the rural sector. The disparities can be discussed in four principal areas, viz., social; economic; medical; technological.

#### *Social*

Rural society has certain inherent strengths and weaknesses which either favour or prejudice effective rehabilitation of the disabled. Among its assets are that the rural society is close knit where inter-personal relations are more humane, with a distinctly greater concern for each other than is likely to obtain in the impersonal urban setting. Nor do people in rural areas suffer from a sense of anomie. Moreover, social institutions such as family, community, church, etc., are still strong and exert a cohesive influence on the community.

The same close knit pattern of living, however, also works as a handicap, insofar as the handicap or the disability gets to be exaggerated. Other negative factors operative in rural society are: (a) the influence of traditional beliefs and biases which unnecessarily stigmatise the handicapped person and interfere even with the scientific treatment of the disability; (b) popularly held beliefs and attitudes towards disability (particularly genetic deformity or abnormality of any sort, leprosy, etc.) are particularly oppressive in rural areas where even normal social interaction and functioning of the disability affected family is strangled. In a broader perspective these social forces are not unique, just as in India, they are well known in other parts of the world also. When because of the functional limitations associated with an impairment or because of the stigmatisation of the disabled person he or she is not permitted to grow and fulfil a traditional role, the individual is very likely to become a non-person, an outcast.

#### *Economic*

Several economic characteristics peculiar to the rural sector are not conducive to rehabilitation of the disabled. The fact that average income



levels are low and a substantial segment of the rural population operates considerably below subsistence level also places economic constraints on the disabled to either afford corrective medical care or to secure suitable work opportunities. These tend to consign the disabled individual virtually to unemployment and to place him invariably on the dole of well-meaning relatives, friends and associates.

Another negative factor is the virtual lack of horizontal economic mobility.<sup>4</sup> Professional and vocational choices in rural areas are still largely pre-determined by sex, caste, class, social standing, etc., of a person. In the case of a disabled person, these economic sanctions for or against a profession are easily discarded. Unless we are able to reform the prevailing attitudes regarding vocational options, there can be no possibility of successfully retraining the disabled for their vocational rehabilitation.

### *Medical*

The absence of an adequate medical and public health infrastructure in rural areas is a major hurdle in reaching even minimal rehabilitation care to the disabled in the rural sector.

### *Technological*

Here, we can revert to what we have tried to bring out earlier namely, that prosthetic and other types of rehabilitation technology is, so far, generally focussed on restoring functionality in an *urban* and *westernised* milieu. There is little appreciation of whether, and how, such technology can be harnessed to meet the real felt needs of the *less sophisticated* and *non-westernised* rural environment. Such an approach would necessarily involve a departure from the 'cosmetic' ingredients in existing rehabilitation towards the formulation and popularisation of inexpensive, simpler, and more functional appliances. This, in turn, necessitates setting up of more research and development centres.

Another function of such centres would be to help formulate clearer priorities among, and viable methodologies for, the various component areas of rehabilitation, *viz.*, detection, diagnosis, physical restoration through surgery and fitting of appliances, vocational rehabilitation, etc.

## PLANNING FOR REHABILITATION : SOME POINTERS

In the light of the above analysis, it is possible to outline certain basic tenets in planning for rehabilitation:

1. Physical and social barriers exclude people with disabilities from

<sup>4</sup>It may be possible for a person to advance vertically in the sense that a small farmer could become a big farmer. But horizontal mobility enabling a cobbler to become a carpenter or a farmer would be somewhat difficult.



full participation. It is only through intelligent social policy and action that these barriers can be removed.

2. Stigmatisation and prejudices arise out of social attitudes. It is, therefore, necessary to develop an understanding about disability, awareness of the rights of the disabled and social responsibility of the state and the community.
3. If social assimilation is inherent in rehabilitation then rehabilitation has to be treated as a partnership between the state and the community. Non-governmental organisations have a very significant role to play in this direction.
4. Rehabilitation should be closely related to the immediate environment of the disabled individual.
5. Rehabilitation should be functional and not cosmetic, in the sense that it should not restore merely superficial functionality to the disabled person. A prosthetic appliance, for instance, should not only complete the physical 'gap' but also genuinely assist the disabled person to harness that appliance towards achieving greater environmental mobility as also acceptance by the community.
6. The totality of rehabilitation should be attempted, in that, in addition to functionality, what should be restored to the disabled are his economic independence or capacity and his social assimilation in society.
7. Rehabilitation should not be pursued in isolation. What this requires is an appreciation that simply by giving of an eye, a limb or a skill, rehabilitation is not achieved, what we have to do instead is to plan for a whole society and to influence social values as well as social assessment of disability.
8. Rehabilitation should be viewed as a total community service involving a combination of preventive, curative and servicing aspects. Preventive action involves specialised attention to specific rural phenomenon such as burns, farming accidents, etc. Curative aspects involve the creation of rural based treatment, prosthetic and rehabilitation services. Servicing refers to a maintenance function and is aimed at enabling the disabled person to utilise a specific appliance, tool, or skill, on a sustained basis.
9. *Specialised approaches* to help meet the disabled's needs in the rural areas need to be developed. These, in turn, require more precise appreciation of the incidence, causative factors, operational and other difficulties faced by the disabled, societal attitudes and pressures, socio-economic ramifications of disability in rural areas, etc. Towards that end, systematic data collection and applied research activities need to be mounted, although lack of availability of such vital information, as we have pointed out earlier, should not defer rehabilitation programmes *per se*.



10. The existing concentration of rehabilitation services in urban areas should be decentralised and democratised in favour of rural based populations.  
It is evident that city-centred rehabilitation planning will have to be consciously and substantially revised in order to take into account the needs for minimal, if not adequate, coverage of rural areas. As a part of this decentralised planning, it would be desirable also to promote community-based rather than rehabilitation centre-confined prevention, detection, diagnosis, treatment and training.
11. *Appropriate technology* should be greatly encouraged. Since the process of taking the service to the people is costly as well as time-consuming, it is desirable that appropriate technology be promoted by planners of rehabilitation. Although appropriate technology is being advocated in many sectors it is felt that nowhere is it more urgently required than in the field of rehabilitation in the rural sector where, simpler and least costing devices need to be evolved to meet the functional requirements of the disabled. Appropriate technology is also required to develop rehabilitation tools which are more socially acceptable as well as viable in the context of the rural economy. These are problems peculiar to the rural sector and should elicit a responsive technology.
12. *People's participation* should be heavily drawn in. In recent years, as the success or failure of development projects has been traced often to the presence or absence of people's participation, the latter has become a crucial variable in ensuring the efficacy of development planning. By participation is meant not only drawing in people (*viz.*, the family, the community, etc.) as a material and manpower resource, but also as a sounding board for judging the validity of the rehabilitation action envisaged. Participation also implies the widest possible utilisation of the handicapped persons themselves in planning and managing of services. It is only then that the credibility gap between the rehabilitation services and its clientele would be reduced.
13. *Innovative experiments and success stories* involving the effective resettlement of the disabled in the rural sector should be highlighted and carefully studied for their wide replication. In Asia, for instance, there are several outstanding examples of rural-based rehabilitation which can be applied in other countries or regions.<sup>5</sup> Such inter-

<sup>5</sup>Amongst others are experiments in poultry, piggery, farming, etc., by leprosy-affected or other disabled groups which are all highly productive and worthy of emulation. Another set of examples are of efficient economic projects (such as, petrol stations, consumer retail shops, etc.) that are jointly run by a group of different disabled types. In Maharashtra, we have an outstanding success story in the form of a project for rehabilitation of the



change and transmittal of approaches, experience, etc., will help develop better and varied alternatives for rehabilitating the disabled population residing in the rural sector.



*(Continued from previous page)*

leprosy-affected. Known as 'Anandvan' (literally a forest of happiness), this centre which began initially as a care centre for the leprosy affected families has today become a focal point for regional and community development. Apart from running profitable economic activities, the centre has become a demonstration project for successful dissemination of literacy, public education and awareness, and shaping of attitudes towards the disabled and their rehabilitation, etc. The centre also combines the able-bodied with the disabled in a joint pursuit of its objectives.

## Is Disability a Handicap—And Need it be Perpetuated ?

P.P. Trivedi

**A** DISABILITY is no handicap as there are ample reserves in a human being to compensate for the disability by drawing upon other abilities. A blind makes up for the loss of sight by higher sensitivity to sound and touch and a phenomenal memory. A person without both legs climbs the Alps on wooden legs. A woman bedecks her artificial 'Jaipur foot' with nail polish, toe-ring and silver anklets.

In Baba Amte's Maharogi Sewa Samiti at Anandvana, the so-called disabled—many of them burnt out cases of leprosy—contribute substantially not only to the income of their families but to the economy of the area and the nation. The single main source of supply of vegetables in Chandrapur district are these people.

It is, therefore, a misnomer to call them handicapped or disabled. It is frequently said that they should be *accepted* for their abilities. But it is not a question of acceptance. They are a part of a family of human beings and each has a place. Only their functional abilities are different from the majority of population and the activities and social attitudes should cater to their different abilities.

According to the United Nations, roughly 10 per cent of the population of a country suffers from a permanent or long-term disability. In India the number may be more and is on the increase due to improvement in survival rate of disabled/weaker infants, increase in average life expectancy, increase of x-ray radiation, increase in road and industrial accidents, etc.

### NEED THERE BE SO MANY DISABLED?

About 1 to 1.5 per cent of the population, that is, 6 to 10 million are without sight; half of them are in this state due to cataract which can be easily operated upon to restore vision. We add *one* million fresh cases per annum to the cataract patients. Our present capacity is 0.6 million operations per annum. There are difficulties of qualified ophthalmologists, but surely this can be an area for international cooperation. At the present rate there is no relief in sight for them even till the turn of the century and the so-called beginning of the era of 'Health for All'.



There are the blind by birth, and the blind due to various deficiencies and diseases. Genetic counselling for blindness by birth and control of deficiencies and diseases for the others need improvement.

Considerable advance has been made all over the world regarding services for the orthopaedically handicapped. But, unfortunately, India has copied the models from the developed world. Indigenisation of technology based on local craftsmen, resources, and socio-culture is necessary. Some leading orthopaedic surgeons in the country are aware of it but compared to the magnitude of the problem, the effort on these lines needs to be intensified. There are cases where qualified orthopaedic surgeons failed and traditional bonesetters succeeded. We have failed to take advantage of the existing fund of knowledge with them. The concept of lighter bonesetting materials for broken bones which have come into vogue in the developed world now was very much in practice by the traditional bonesetters. An interaction of the medical personnel with traditional healers may be mutually rewarding.

Training in physiotherapy and occupational therapy is also based on foreign ideas but which needs to be developed on local traditions, skills, occupations, materials and even prejudices.

The whole concept of a hospital with impersonal services and segregation of patients from the families is again foreign. I am sure the recovery would be faster and better if there is more humane and dignified atmosphere in our hospitals.

It is estimated that about two out of the three orthopaedically handicapped in India incur a long term disability due to polio and a majority of them are from the rural areas and are young children. It is really criminal to make so many persons suffer when the disability can be easily prevented with vaccination. There is shortage and irregularity of vaccine supply and it has to be imported. Domestic capability for production of vaccine has yet to be built. Here again is an area for international cooperation for eradication of polio as a crash programme within 3-5 years.

India has the largest number of reported leprosy patients in the world; about 9 million (out of whom one-fifth are infectious leperomatus cases). The basic drug Dapsone was in short supply in spite of adequate production capability, and had to be imported. This has been rectified recently but the production schedules will need to be kept under constant watch. Leprosy vaccine is in the offing but there are the usual delays. It is a matter of deep concern that the stigma attached to leprosy still continues and even the medical personnel hesitate to come forward for their treatment. They continue to receive treatment in separate wards even isolated from other infectious patients. They are denied the use of public conveyance. Leprosy is not more infectious than T.B. and both T.B. and leprosy can be cured, a community health volunteer in Mandwa project says. But even an educated public has to understand and accept this.





The number of the orthopaedically handicapped, due to accidents, is on an increase. The accidents in small industries including thrashers take a heavy toll. It should be possible to devise these machines in such a manner that they cannot work unless the safety mechanism operates. Such machines may not be sold unless the users undergo compulsory training for a prescribed period.

Measles which leads to blindness, deafness, etc., in some cases, can now be prevented with vaccine. Smallpox which used to be a major cause for disabilities, has ceased to be so. But it will need constant vigil and a ready stock of vaccine for any sudden unanticipated flare-up.

In the tribal areas, fire and tree-fall are major factors contributing to accidents. It should be possible to analyse the causes and build, in the non-formal and formal educational programmes, proper precautions and work habits. With improvement in traffic control, transport, wireless and hospital emergency services, the number of the disabled due to road accidents can be reduced.

About 1 to 1.5 per cent of the population is estimated to be mentally retarded. About 1 per cent of the population suffer from epilepsy at a given time and contrary to the general belief its incidence is as high in the rural as in the urban areas. It is heartening to note that most of the persons (as high as 75 to 90 per cent) suffering from epilepsy and psychosis can be rehabilitated by early intervention and regular follow-up. The model for delivery of mental health services in the rural areas through the public health centres, as developed by the National Institute of Mental Health and Neuro Sciences, is just being discussed.

Congenital malformation in children in many cases is reported to be due to overdrugging during pregnancy specially during the first three months. Greater orientation of medical personnel to drugs hazards is necessary.

#### HEALTH EDUCATION FOR THE PUBLIC

It is a scientifically established fact that consanguineous marriages increase the risk of disabilities. Imaginative and sensitive public education on this personal matter calls for concerted effort.

In order to draw upon the different abilities, knowledge of the sources from where corrective or rehabilitative services are available, provision of these services at the cheapest rate, in the simplest manner, and easy to maintain are crucial. Like 'Mamajee's' in Meghalaya or wayside automobile workshops owned by illiterate but first-class mechanics, it should be possible to provide such aids and appliances to the millions of the handicapped, dispersed over the far flung tribal, hilly and rural areas (and also confined to urban slums) which can be conveniently maintained and repaired.

The area of prevention of handicaps has also not received adequate attention. Between the ministries of health and social welfare the dialogue





at different wave-lengths continues.

There has been over concentration on special services in isolated institutions while the proper attitude should have been to integrate them as much and as early as possible with the normal stream of national activity. In order to undertake integrated education of these children with normal children, we need trainers and trained teachers and develop models suitable for rural areas where population is sparsely spread out. A teacher aptly remarks, "...I have come to realise that working and playing together is proving beneficial not only to blind pupils, but more specially, I think, to the others. The acts of patience, unselfishness and thoughtfulness performed without conscious effort for their handicapped classmates is bringing out the best in their nature...."

The disabled constantly being looked down upon or pitied upon, cease to respect themselves. Unless their respect and confidence is restored through work, they will really become handicapped instead of being participants in the daily chores of life. Baba Amte says, "Work builds, charity destroys".

Considering the vast magnitude of the problem, could special employment exchanges be a solution to the need for employment? Much greater emphasis on self-employment of the disabled in their normal place of residence is necessary. A chain of rural training institutions needs to be planned to develop relevant skills and to retain affinity with their normal living conditions.

It is being debated upon in India whether a blind can be a medical doctor. A blind may have some difficulty in surgery but he should have no problem in handling medicine, and in fact by virtue of his extra-sensitivity to touch, sound and also humane behaviour, he excels an ordinary medical officer in diagnosis and also has a healing touch.

The introduction of a rehabilitation therapist at the primary health centre level, training of a community health volunteer in detection of disabilities, early intervention and follow-up, school and preschool health services, orientation of medical and para-medical professionals in preventive and rehabilitative services are some of the aspects, among others, under consideration.

There are thus limitless possibilities of prevention and, if the disability occurs, of rehabilitation. A disability need not tend to become a handicap. And, therefore, rightly is the question asked: 'Need disability be perpetuated?'



## Reservation for the Handicapped: Constitutional and Programmatic Issues

Bata K. Dey

**L**IKE THE reservation for scheduled castes/scheduled tribes (SC/ST), reservation for the handicapped has also been provided for by the Government of India since 1977 through executive instructions. The present scheme of reservation for the physically handicapped for group C (class III) and group D (class IV) posts is: the blind 1 per cent; the deaf 1 per cent; and the orthopaedically handicapped 1 per cent; and so total 3 per cent.

Under the reservation for SC/ST, the percentages (15 per cent and 7½ per cent respectively) are related to the SC/ST population and the total population of the country according to the census report of 1961. The handicapped reservation is not, however, based on population criterion. Indeed (it is sad though) there is no reliable census of the handicapped or the disabled in this country. The early censuses of this century did make a reference to the blind, deaf-mutes, etc., but no dependable figures emerged, primarily because there has been no clear-cut and universally accepted definition of disability. In the National Sample Survey, during the years 1959-61, 1969-70 and 1972-74, attempts were made to compile this information but again criteria problems and definition difficulties probably led to very low figures. According to the presently accepted definition of disability, at least 5 per cent (as against internationally accepted 11 to 12 per cent)<sup>1</sup> of India's population can be considered as handicapped which would mean about 30-35 million people. The figures (which are mere guesses) of the disabled, though arrived at through sample surveys have necessarily to be tentative but, still, it will be worthwhile to note them, if not for their total accuracy, at least for a pragmatic start, i.e., from an operational angle. The three broad categories of the handicapped which form the foci of discussion in this paper and their probable numbers are:

*Blind:* Estimates of the blind vary from 1 million to 9 million, though the

<sup>1</sup>It appears to me that this high international percentage, as compared to our national percentage, has something to do with definition differences; otherwise, in the context of India's abject poverty, malnutrition, ill-health, substandard hygiene, etc., the figures in this country have no explicable reason to be so low as to be less than 50 per cent of the global figure.



blind, with the nearly blind. will be closer to 9 million.

*Deaf:* While the number of the totally deaf may be small, there are about 1.5 million people with an 80 per cent hearing loss. (With all people with hearing deficiencies, the figure may as well go up to 35 million).

*Orthopaedically Handicapped:* The total number is estimated at 15 million.<sup>2</sup>

Since definition of these groups of the disabled poses problems about identification, it is better to adopt particularistic definition as to whom we would term as the blind, the deaf and the orthopaedically handicapped for the purpose of the reservation for the handicapped in the government service. They are:

*The Blind:* The blind are those who suffer from either of the following conditions:

- (a) total absence of sight;
- (b) visual acuity not exceeding 6/60 or 20/200 (Snellen) in the better eye with correcting lenses;
- (c) limitation of the field of vision subtending an angle of 20 degrees or worse.

*The Deaf:* The deaf are those in whom the sense of hearing is non-functional for ordinary purposes of life. They do not hear, understand sound at all events with amplified speech. The cases included in this category will be those having hearing loss of more than 90 decibels in the better ear (profound impairment) or total loss of hearing in both ears.

*The Orthopaedically Handicapped:* The orthopaedically handicapped are those who have a physical defect or deformity which causes an interference with the normal functioning of the bones, muscles and joints.

#### SCHEMES OF RESERVATION

For these defined categories of the handicapped, the Government of India has provided for reservation in class III and class IV posts to the tune of 3 per cent of the vacancies (@ 1 per cent for each of these categories) arising in any recruitment year. The other aspects of this scheme of reservation are:

1. In 100 point rosters, 3rd, 37th and 70th points will be reserved for blind, deaf and orthopaedically handicapped persons respectively.

<sup>2</sup>Collected from the discussion papers for the seminar on "Social Handicaps and Physical Disability—Role of Government and Voluntary Agencies", held in New Delhi on August 10-12, 1981.



2. The following jobs have been identified for the blind persons:

*Blind:* Announcers at railway stations, bus stops and airports (T), Cane weavers (T), Instrumentalists (staff artists) (T), Maseurs (T), Musicians (T), Music Teachers (T), Office superintendents (H), Packers (T), Stenographers (with dictaphone and digital typewriter), Teachers (primary—T&A), Telephone operators (small boards with electronic beep and embossed digits), Lathe operators, Press operators, Stampers, Weavers, Packers, Drillers, Fitters, Chippers, Teachers in Social Sciences.

*Partially Blind:* Dak messengers, despatch clerk(T), Gardeners (T), Gestetner operators (T&A), Liftmen (T & Digital controls) Peons, Receptionsts (T&A), Retiring room attendants, Sweepers, Watermen (T), Waiting room attendants, Lottery ticket sellers.

Explanations: T—with training, H—with a helper, A—with aids.

3. If, in any year, the vacancies reserved for these categories are not filled, the reservations should be carried forward for a period of up to two recruitment years.
4. *Inter se* exchange of vacancies is permissible if candidates belonging to a category of persons are not available or if the nature of vacancies is such that a given category of persons cannot be employed.

This reservation for the handicapped raises several issues of significance. First, doubts have been raised as to whether reservation for the handicapped can be constitutionally supported by reference to Art. 16 (4) or whether it could be supported independently of Art. 16 (4) on the basis of rational classification or permissible discrimination under Art. 16(1) itself. Equality of opportunity in Art. 16(1) would seem to be violated straightway by such reservation unless either Art. 16(4) can be invoked or, independently of it, the classification of the handicapped could be supported under Art. 16(1) itself. The question which needs to be answered, for the purpose of Art. 16(4), is whether the handicapped persons could be said to be 'backward class of citizens'. No doubt, they form a class of citizens but could they be called 'backward' within the meaning of the expression used in Art. 16(4)? The Supreme Court has held that a backward class must be backward in the sense SC/ST are backward and the words 'socially and educationally', used in Art. 15(4) have to be taken cumulatively to qualify such backwardness. It may, therefore, be difficult to admit into the fold of backward class of citizens any category of people other than SC/ST and/or those who could be, without doubt, brought within the framework of 'socially and educationally backward' people as enjoined in Art. 15(4).



## CONSTITUTIONAL JUSTIFICATION FOR RESERVATION

It has sometimes been argued that Art. 41 of the constitution under the directive principles of state policy would provide sufficient constitutional justification for making reservation for the handicapped. For facility of reference, Art. 41 is quoted below:

## Article 41 :

The state shall, within the limits of its economic capacity and development, make effective provision for securing the right to work, to education and to public assistance in cases of unemployment, old age, sickness and disablement, and in other cases of undeserved want.

It is clear that Art. 41 cannot be of much help in validating the reservation under the constitution. It is no doubt possible for the state to do all that the directive principle in Art. 41 enjoins it to do in any diverse ways, but regarding reservation of appointments and posts under the state, it is quite another matter; for Art. 16 specifically forbids it, subject to the provision in Art. 16(4). Legitimacy of reservation in public employment can and must flow only from Art. 16(4) and so long as this Article cannot be interpreted to include the category of the handicapped persons within the denotational and connotational jurisdiction of the backward class of citizens. it will remain open whether reservation for the handicapped is constitutionally in order in terms of Art. 16(4).

Since reservation cannot be justified under Art. 16(4), the only way in which the reservation can be sought to be supported is by means of the reasonableness of classification permissible under Art. 16(1). A classification is permissible provided it can be adjudged as being reasonable by reference to the purpose of the law, that is to say, having a rational nexus with the object. Perhaps there could be a rational classification for a favourable discrimination on the basis of physical handicap. An easier course, technically speaking, would perhaps be to issue directives to central services and the public sector not to discriminate against, or deny, the handicapped—the blind, the deaf and so on—equal and adequate job opportunities on account of a physical handicap where the categorised jobs are such that the handicapped, notwithstanding their particular disability could do justice to the jobs. It would not then be reservation but essentially a measure to remove what would otherwise be a virtual bar against the physically handicapped on the ground of unsuitability or ineligibility. Indeed, the handicapped persons barred from all employment under the state as a general rule on the ground of physical ineligibility could themselves complain of violation of Art. 15(1) where they are capable of doing jobs in employment suitable to them, notwithstanding their particular handicap.



### JOBS TO THE HANDICAPPED WITHOUT LOSS OF PRODUCTIVITY

From this we come to the second significant question that has been raised in relation to reservation for the handicapped. That is, why make reservation for the handicapped workers and worsen the already bleak prospects of employment for normal citizens? This writer remembers a top civil servant once proclaiming when the issue of allowing ex-TB, ex-leprosy patients as candidates for competitive examination was put before him that in the country there was no dearth of able bodied youngmen. It has been argued that the vulnerability of the handicapped workers justifies a measure of special protection to promote their employment opportunities which obviously will be in furtherance of the directive principles of the state policy in Art. 41. It should not be difficult to identify suitable jobs for the different types of handicapped people without loss of productivity and to provide preferential placements to them against such jobs.

Given suitable education and training, the handicapped can undertake many kinds of jobs without loss of productivity. The development of modern aids and appliances has further widened their occupational choice. A number of studies have shown that they are as productive as other workers and are less prone to absenteeism. A policy of selective placement can be adopted after identifying the types of jobs that can be performed by the different categories of the physically handicapped, with or without special equipment. It should not be forgotten that the issue here is not one of arithmetical computation of efficiency, or the absence of it, but a wider question of socio-moral (coupled with economic-cum-human considerations) obligation of the nation to an unfortunate segment of its citizens. It is sad that no much headway could be made in this connection since 1950, in spite of Art. 41 of the constitution. This could be due either to prejudice on the part of employment agencies regarding the productive capabilities of the handicapped personnel or lack of understanding about what the handicapped can do in low or even intermediate technology or both.

It seems unavoidable, therefore, to have to resort to more positive measures to facilitate the employment of the physically handicapped through reservation of a certain percentage of vacancies in their favour. It is in this context that the Prime Minister of India's statement in Parliament in December, 1971 becomes relevant. The Prime Minister said that she would bring forward a legislation making it obligatory for all employers (who employ more than 25 people in the public as well as in the private sector) to reserve a certain proportion of their vacancies for the physically handicapped. Finally, the Government of India in 1977 issued orders providing for reservation for the handicapped, as indicated above. (As in the case of SC/ST, where reservation has been provided through executive instructions, it was thought that it would not be necessary to go in for statutory enactment for providing for reservation in favour of the handicapped).

It is interesting to note that in the following countries in the world quotas



have been made for the disabled :

<i>Country</i>	<i>Quota reserved for the disabled</i>
Argentina	Certain occupations have been reserved for the disabled.
Austria	Certain vacancies in the public services are reserved for the disabled.
Australia	1 for the first 15 and 1 for every 20 vacancies thereafter are reserved for the physically handicapped.
Belgium	Varying percentages.
Brazil	2 per cent.
Federal Republic of Germany	The quota varies from 6 per cent to 10 per cent and is applicable to the blind and to those handicapped as a result of industrial accident or disease.
France	10 per cent vacancies are reserved for the war disabled. Within this quota, 3 per cent vacancies are given to civilian disabled.
Greece	7 per cent
Holland	2 per cent
Italy	Overall quota is 15 per cent and is applicable to establishments employing 35 persons or more. Within this quota specific percentages have been laid down for the war disabled, civilian disabled, the deaf, etc.
United Kingdom	3 per cent.

It is comforting that besides the Government of India's reservation percentages, several state governments in this country have also set apart certain percentages of reservation for the handicapped as given below:

<i>Name of the State/Union Territories</i>	<i>Reservation (percentage)</i>
Andhra Pradesh	3
Assam	3
Arunachal Pradesh	3
Chandigarh	3
Delhi	3
Dadar & Nagar Haveli	3
Gujarat	4
Goa, Daman & Diu	3
Haryana	3
Himachal Pradesh	3
Jammu & Kashmir	3
Karnataka	2
Maharashtra	3
Madhya Pradesh	3
Orissa	1
Pondicherry	3
Punjab	3
Rajasthan	2
Tripura	2
Uttar Pradesh	2
West Bengal	2





## PROBLEMS OF THE DISABLED WIDER THAN JOBS

It is well to remember that reservation in class IV and class III posts under the central government is not a broad-spectrum antibiotics to cover the various ills of social handicaps from which the disabled suffer. It is only one of the small ways to tackle their problem, the solution of which should not, therefore, start and end with reservation alone. The problems of the disabled or the handicapped are myriad and their causes are also diverse. The complete lack of appreciation of their abilities to face up to the normal tasks, as are performed by others in society, the prejudices against and the negative cultural responses to them, because of their disability, the equally degrading (if not damaging) attitudes of pity and charity, mechanical show of compassion non-feelingly meted out, etc.—all create major barriers to their socio-psychological and economic adjustment with the mainstream of social life. Well-planned investigative research projects are required in our country (without, of course, making the handicapped merely models of academic study) to see if the disabled cannot be gainfully employed, with the aid of special equipments rendered possible by technology, in jobs and professions earlier considered taboos for them. The concern for the handicapped came to be accentuated only after the World War II, in relation to the war-disabled in particular—in USA, special concessions are available for war veterans, but in our country, also, this problem became acute perhaps after the wars that were fought in early and mid sixties, and seventies—though a general feeling of ‘duty’ and sympathy towards the handicapped based on religious or philanthropic sentiments, has been prevalent in the minds of at least some people, though at a low key. Along with, and independent of, other systematic programmes of rehabilitation to the war-affected or war-injured which naturally acquire some urgency and conspicuousness—what is necessary is the continuous peace time programmes<sup>3</sup> for bridging the gap in the ability of the disabled, and in certain situations, in restoring the lost capability, to contribute to the total societal development. This serves two purposes simultaneously: the society gains, and does not lose, the services and the contribution of a section of society, considered to be only a drag on it; and the handicapped themselves can conquer their disability, frustration, self-pity, guilt consciousness, etc., to be fuller citizens.

The rehabilitation programmes of the handicapped cannot obviously be conceived in generic terms, though there has to be certain commonality of features amongst them. Essentially, they have to be tailored to suit the specific requirements of particular categories of disability. Nevertheless, one

<sup>3</sup>Peace time rehabilitation programmes in relation to the handicapped must mean bringing them to a state of economic independence and social acceptance. To realise these twin objectives, in the complex and peculiar society of today, the parents, the handicapped themselves, the society and the government must play a crucial role.





can note that:

- (a) there has to be an economic component to such programmes;
- (b) institutional support system must be generated;
- (c) not merely official assistance but, more importantly, intervention by voluntary organisations, with their flexible functioning process, approach charged with non-selfish human compassion, and motivation of social welfare, will have to be sought. Indeed, it is an area where the whole community must have to be involved;
- (d) there has to be stepwise well coordinated perspective plan in this field and it has to be ensured that once a programme is on, or midway through, funds are not cut or diverted to more 'important' conspicuous areas;
- (e) the schemes must not only be diagnostic in nature but should be simplistic in implementation, practical in outlook and must fit in, as part of an overall plan, with the ultimate object of total economic sustenance and integration of the handicapped in the mainstream of life.

Some of the on-going programmes that are now available to the handicapped persons of the three categories under discussion in this paper could be listed.

*The Blind:* In regard to education and welfare of the blind in India, the Ministry of Education instituted a unit to deal with the problems and unified the different braille codes and standardised them in a common code called Bharati Braille. The Government of India has been running a large national centre for the visually handicapped, which has a model school for the blind children, a training centre for the adult blind, a workshop for making braille appliances, a sheltered workshop, a central braille press, a national braille library for the blind with a talking book studio. The Government of India has also a very liberal policy of giving scholarships to all the major categories of the handicapped including the blind, which enable such students to study in the integrated scheme, right from the primary stage of education to the Ph.D programme. The government has also undertaken the running of 4 regional teacher training centres in Bombay, Delhi, West Bengal, and Madras. There also are 22 special employment exchanges for the physically handicapped including the blind.

With a view to improving the effectiveness of such programmes, the following suggestions are worth consideration:

1. Vocational training and vocational counselling should be a compulsory subject in all schools for the blind. All institutions and schools for the blind should also have a placement officer who would cater to the clients of his own institution.



2. The media of mass communication and press agencies should be reinforced to publicise the achievements and capabilities of the blind and public awareness should be aroused about the potentialities of each trained blind individual.
3. Concerted efforts both on the part of the government and voluntary agencies should be made to survey all categories of industries to secure remunerative employment for the blind, commensurate to his training.
4. Sheltered workshops should be opened in all the states and they should not only include clients who, for unavoidable circumstances, are unable to work in open industries. They should also enrol blind clients who, on completion of their training, are yet awaiting employment in open market. The gap between the training period and gainful employment should be minimised.

*The Deaf:* At the moment, there are 120 schools for the deaf in different states and they are imparting education to about 10,000 children. Most of these schools were started on private enterprise. The government has also started its own schools in many states and given grants-in-aid to the private schools. There are also about 12 teachers' training centres in the country. The following facilities are also available for the vocational training for the deaf:

- (a) Five years' course in commercial/fine arts leading to a national diploma in arts through the various arts colleges.
- (b) Sheet metal work, wiremanship, fitting, welding, painting, turning, machine-operation, instrument mechanism, manufacture of radio components, etc., at the national centre for the adult deaf at Hyderabad.
- (c) Photography, press-work and technical training by the All India Federation of the Deaf.
- (d) Book-binding, tailoring, etc., at the training-cum-production centre.
- (e) Some of the suggested programmes could be:

1. In big cities diagnostic centres should be established to carry out early differential diagnosis, offer advice on care and training at home and other similar matters. A coordinated interdisciplinary approach of experts from different disciplines (medical, social, psychological and educational) will be required for this purpose.
2. Suitable hearing aids should be provided free or at subsidised rates to every young deaf child.
3. More nursery schools with programmes of parent guidance should be opened by government as well as voluntary bodies.
4. Mass media of communication should be mobilised for arousing



public awareness regarding problems of deafness because unless people understand these, they cannot help rehabilitation.

5. Industries should be persuaded to provide on-the-job training for the deaf.
6. More training-cum-production centres should be set up by the government as well as private organisations, if necessary, with the assistance of world agencies.
7. Each State should have at least one middle school for the deaf with a plan to raise it to high or higher secondary school.
8. Special arrangements should be made for instructions in trade theory and reading and drawing; ITIs and apprenticeship programmes may be thrown open to the deaf.
9. Having regard to the existence of two economies in the country—the industrial economy and the agricultural economy—separate categories of crafts should be drawn up for the deaf to conform to these two economies:

- (a) *Urban Requirements*: Typists, tracers, compositors, packers, fitters, black-smiths, moulders, welders, carpenters, turners, electricians, machine-men, pattern-makers, tailors, book binders, launderers and dry cleaners, photographers, etc.
- (b) *Village Requirements*: Poultry and animal husbandry, pottery, haircutting, black-smithy, shoe-making, tailoring, carpentry, gardening, weaving, etc. Some of the crafts may be included in both.

*The Orthopaedically Handicapped* : Programmes for the orthopaedically handicapped could be considered on the following lines:

1. *Job Opportunity*: Worthwhile incentives should be given to employers in the private sector so that they can employ orthopaedically handicapped. This can be either in the form of tax exemption or some direct incentive tied to the number of the orthopaedically handicapped given jobs in an industry. Those orthopaedically handicapped who are seeking self-employment should be allotted infrastructure facilities on priority and subsidised rates. Interest free bank and institutional finance should be available to them.
2. *Children's Education*: The children of the orthopaedically handicapped should have priority for admission in schools of the parent's choice. Where justified, part or all educational expenses could be reimbursed expeditiously. In case of exceptionally bright children, expenses for higher education in India or abroad could be fully met by the government.
3. *Transportation and Travel*: As a general policy, the orthopaedically



handicapped should be allowed free use of nationalised public transport along with an attendant, if required. Those orthopaedically handicapped who cannot use public transport because of their disability should be provided with suitable conveyance such as motorised tricycles or cars fitted with gadgets for disabled at cost, or at subsidised rates.

4. *Medical Facilities:* Orthopaedic centres with full modern facilities such as artificial limbs, therapists, etc., should be started in many more localities. Research centres for improving artificial limbs to provide greater mobility should be established. Artificial limbs which cannot be developed in our country, should be freely imported.
5. *Pensions:* Pensions for the war disabled or those disabled on duty could be modified realistically. The pension structure for the disabled should be in line with the needs and the degree of disability. The greater the disability, the higher the pension.

The government has no doubt launched a large variety of schemes to assess the backward and the undeveloped areas. There is no reason why similar institutional arrangements cannot be worked out for the disabled. On the lines of backward areas development corporations, backward classes development corporations, tribal development corporations, etc., the suggestion for setting up of a corporation for the disabled under the rubric of a handicapped development corporation would be considered. These corporations could act as channels for funnelling of public and institutional finances and also for drawing up the reservoir of individual charitable disposition; it could also act as a nucleus in the triggering of a spate of new research in development of prosthetic aids and new techniques designed to suit the genius of the disabled; a suitable infrastructure for providing the necessary inputs and marketing facilities; for identifying projects and preparing project reports and, lastly, for mobilising and coordinating the individual and collective voluntary efforts.

It is obvious that the state, with its limited resources crying for distribution amongst competing claims cannot fulfil the growing needs of the handicapped. It can at best be expected to play the role of a 'catalytic' agent; but the problems tormenting the handicapped being basically human-cum-social in nature can be better dealt with, effectively and fully, only when the total participation of all concerned sections of society is forthcoming. In other words there has to be a sympathetic and compassionate national policy for the handicapped.

## Physical Handicap: The Problem of Definition

**Meenakshi**

**T**HE INCREASING number of the disabled all over the world presents a depressing picture. According to the latest information collected by a survey made by the Congress of the International Rehabilitation in 1968, 450 million people are listed with impairment, physical or sensorial or mental of sufficient severity all over the world. Based on anticipated population growth and other factors, it was projected that an additional 3 million impaired persons should be added to the world total during each year of the 1970s. Specific statistics are not available in all countries and definitely not in India; some sample surveys were however conducted in India on the basis of which we can estimate the approximate number of the disabled. On the basis on a Bombay sample survey, the Director General of Employment estimated in December, 1959 that there was a total of 8,823,000 disabled persons (2.3 per cent) in India in 1956. Based on a Delhi sample survey, an estimated total of 13,440,000 (3.5 per cent) was obtained for the same year (Taylor & Taylor, 1970). It is found by different surveys that the major types of the disabled, out of the total disabled, are the visually disabled and the orthopaedically disabled. In some surveys like that of Bombay the orthopaedically handicapped constitute the greatest category, while in others like that of Delhi, the blind constitute the major category. The discrepancy between the estimation is probably in part due to variations in the definitions of the handicapping condition used in the studies.

The sociologist's statistics cannot stop at this and to understand the real dimension of the disabled we will have to see beyond the number of the impaired people. Their effect on the lives of their family members and other associates in their community is also to be accounted for. The United Nations Expert Group considering the economic and social implications of the disabled recently concluded that at least 25 per cent of the population, including the impaired persons themselves, are directly affected by the presence of impairment and its consequences (Joglekar, 1979).

### WHO ARE THE DISABLED?

Due to the problem of defining the physically disabled the accurate number of the disabled in India has not been correctly assessed. Different projects



have used the definition according to their specific aim. Discrepancy between the Bombay sample survey and the Delhi sample survey for the same year is an example. Not only for assessing the correct number of the disabled but also for making any policy for the disabled, it is necessary to be clear about the definition of the disabled. What are the different aspects of life affected by disability, and in what way? What are the points which need more attention as far as policy making is concerned? Whom should we call the disabled?

There is no clear cut demarcation between the 'able-bodied' and the 'disabled'. At the outset the term 'disabled' suggests a state of helplessness; something which falls short of the norm or standard, viz., 'physical fitness'. But this standard itself is a misnomer, for it is rather vague. Every individual suffers from some physical limitation or the other, which renders him incapable of performing certain tasks. On the other hand, there is no individual, however severely disabled, who cannot undertake some work. It is often forgotten that despite his permanent disability such an individual still possesses residual resources which are intact and capable of taking on fresh tasks. In fact 'physical fitness' itself is a relative term. It is the functional capacity of the individual for a task. It has no real meaning unless the task or the job, for which the fitness is to be judged, is specified. Physical fitness for an athlete or a soldier may be totally different from that for a white collar worker.

Social prejudice is another factor which governs the concept of physical fitness. A disabled person who can perform all the normal tasks of life, can reasonably be called 'physically fit'. But people are so much obsessed with the idea of branding the disabled as totally worthless that they fail to evaluate his inherent potentialities. "I have never met a normal individual and I do not know what such an individual would be."

The speaker was Dr. Gudmund Herlem, the distinguished recipient of Albert Lasker Award, when he addressed the Eighth World Congress of the International Society for Rehabilitation of the Disabled. He went on to say: "Actually, of course, there is no such thing as a normal individual. We are different in all the thousands of human abilities and activities. We will find large differences among people, and really what a dreadful world it would be if we did not" (Gudmund, 1960).

The term 'normal' is not a statistical concept, but a personal judgement in which we use ourselves as the standard and the subject of our attention as the deviation from the standard. It represents physical or psychological traits, the evaluation of which is influenced by social prejudice and our vocabulary is the vehicle by means of which these prejudices are transmitted.

#### DISABILITY IS ONLY LIMITATION

Generally the terms 'disabled' and 'physically handicapped' are used in an identical sense, but the expert interpretation of these terms is quite unique.





Marvin B. Sussman (1977) defines it by using the term 'Impairment'. 'Impairment' is defined as any deviation from the normal which results in defective function, structure, organisation, or development of the whole or any part of an individual's faculties. Here impairment is of anatomical nature. Disability refers to any limitation experienced by the impaired individual in comparison with the activities of the unimpaired individual of similar age, sex and culture. It leads to a limitation of physical function, whether locomotory, sensory, or affecting any other specific organ. The effects of disability, however, are seldom confined to the pathological conditions alone. In a majority of cases, they extend beyond it, embracing the psychological, educational, social and vocational aspects as well. The disabled face many social disadvantages because of their physical inadequacy, such as a feeling of inferiority, fear of social ridicule, inability to compete with the physically normal people, lack of self-confidence, and limited social participation. The disabled have to adjust themselves to their own disabilities as well as to the uncongenial social atmosphere. Thus they are called upon to bear a double burden, social handicap in addition to the actual physical loss. Handicap is used to describe the disadvantages imposed by an impairment or disability upon a specific individual in his cultural pattern of psychological, physical, vocational and community activities. The degree to which he is handicapped depends on his physical, psychological, and mental capabilities and the social definition given to his impairment. Therefore, handicap is a social condition imposed upon the disabled individual. He feels handicapped and is made to feel handicapped. By the community they are considered as useless members of society. Society treats the disabled as either an object of pity or ridicule. For example in a number of occasions we can see that the disabled is not called by his name but by the term for his specific disability like 'Andha' (for blind in Hindi). Or in certain films the comedian is a person who is either squint eyed or has some other type of disability and that is made a butt of joke.

Thus, more than the disability, it is the social handicap that worsens the life of the disabled. This social handicap has its roots in the stigma towards the physically disabled persons.

There are certain other problems in defining disability. Who is defined as the disabled, and by whom, and in what context? A normal worker with chronic bronchitis, or a professional man who has lost a leg, a young woman with facial disfigurement, or a middle aged housewife with angina, a man suffering from an ill-defined condition which he feels prevents him from working, or a man labelled 'epileptic' to whom no one will give a job? The variables involved in such a list demonstrate the complexity of 'disablement' (Blaxter, 1975). Blaxter mentions that the cause of disability and the effect are again important factors especially when the purpose of definition is to the granting of recompense for disablement. On the basis of the cause of disability, the disabled may be: (i) industrially induced disease or acquired



in armed services; or (ii) by other causes.

Of these two factors of cause and effect, the cause assessment criterion is very particularistic but about its effect it is very vague. Those agencies that deal with disputed industrial injury cases can bear eloquent testimony to this. It is held by many who have to deal with them that the industrially injured tend to exaggerate their disabilities.

#### HEALTH AND SICKNESS CONTINUUM

Blaxter tries to find out a continuum between sickness and health. Most people are 'disable' to some degree. The place on the continuum that the individual finds depends upon factors of perception, identification, cultural concept of normality, social and family environment, and the individual factor of personality, as well as on clinical facts.

When we think about 'who is going to define', we find incompatibility between the clinical and administrative defining systems. Administrative definitions have bipolar distinction—'disabled', 'industrially injured', 'handicapped'. These definitions are designed for a large group of people. Sometimes these definitions become difficult to make, while clinical definitions are easy to make. In less easy cases it is obvious that medical practitioners will dislike firm, permanent labels, and will wish to avoid situations where they are forced into definite prognoses. As Machanic has pointed out, doctors practise within a context of uncertainty. Yet, the administrative structure, necessarily using the medical profession as defining experts, forces the doctor to sign certificates, pronounce people as 'permanently unfit for his usual work'. The administrative structure imposes its own time schedule (*e.g.*, six months is the dividing line between short and long term incapacity) and develop conventions by which the actions of doctors are given arbitrary meaning. Treatment may continue for a considerable time before pronouncement can be made on its ultimate degree of success in restoring a function.

Social handicaps affect different aspects of life of the individual to a smaller or greater extent like family, neighbourhood, school, place of work, leisure time activities and so on. Generally the close relations of a person are of family, neighbourhood, school, and place of work. The presence of the disable create disharmony in the family. Every member of such family has to face bitter experiences. There is a myth in society that out of the blissful eternal union of marriage will come children who are both physically and mentally beautiful and perfect. Therefore, the parents of a disabled child have not lived upto the 'ideal' and have produced an imperfect replica of themselves. This sometimes causes, consciously or unconsciously, guilt as well as a feeling of inferiority in the parents. At the same time, society expects them to be 'super parent'. They must supply enormous additional care, love and attention to their disabled child, otherwise they are 'super bad' (Greer, 1975). And again, if parents do so, the siblings of the disabled feel





the usual sibling rivalry in an unusual, acute form. The disabled becomes the focus in the family on which from all sides strong emotions clash.

The handicapped face a lot of problems regarding education, the first of which is safe environment. The schools are inaccessible and therefore it is difficult for the disabled to go to the normal children's school. Access means the removal of the architectural, transportational and environmental barriers for the disabled. There are educational institutions specially meant for disabled where special teaching as well as access is provided. It is true that in such a segregated environment they could not feel any difficulty. But when they return to the society to lead the rest of their lives they feel insecure because in their special institutions they get familiar to a particular type of environment very different from the ordinary. This highlights the problem of 'integration' of the disabled with others in the society. It would be far better if they are integrated into the school for normal children. Minor changes could, of course, be made in the schools to make them accessible.

#### PURPOSEFUL EDUCATION

For the education of the adult disabled the most important thing is that it should be job-oriented so that they can lead an economically independent life. Though this is applicable in general, for disabled it is of particular importance. Not only vocational training, but jobs should also be given to them. The Delhi survey mentioned earlier has observed that in spite of having had vocational training and getting their names registered in employment exchange, specially meant for the physically handicapped, no one among them could get a job. For female adults, training should also be given in carrying out home tasks in an easy manner so that they feel themselves like normal women in the household.

With the education of the disabled, education of society is also of much importance. The prejudice towards the disabled can be brought to an end through general education by which people should be made aware of the fact that, in spite of the disability of a particular function of a part of the body, the rest of the person is as normal as that of any one else, and is capable of (and deserving to lead) a normal life. Due to ignorance, certain facilities, specially provided for the disabled, remain unused or are misused. For example handrails on the roadside, meant for the handicapped, are used and spoilt by children who play with them; or the handrail in buses for support are not used by the disabled due to overcrowding near the handrails.

Thus the crux of the problem starts with the meaning of disability due to which a disability is changed into a handicap by the community. Existing literature is not enough to tell all about the problems of the handicapped in India. Different aspects of their life need thorough investigation; for example the disabled in the context of the family. This in itself comprises different aspects—parental attitude to normal and disabled children, effect of family



on personality formation, differences between personalities developed in the context of the family and in the context of the rehabilitation institutes, etc. Due to extra expenditure on treatment of the disabled the finances of the family are also strained. What expenditures are stopped to make the family budget balance is also important to know. How does the economic imbalance affect the family? How does economic self-dependence of the disabled affect his personality and his family and what type of social treatment does an unemployed disabled get? In what way do the colleagues and the employer treat the disabled? How does it affect his personality? How does disability affect his performance? In the neighbourhood, the social relations also need investigation. What are the extra curricular and leisure time activities of the disabled? Who are their playmates? And many such questions. Perhaps, after such types of studies, we may be able to tackle the problem of the disabled more accurately and comprehensively.

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## **Welfare of the Handicapped—The Role of Voluntary Organisations**

**G. Ravindran Nair**

**T**HE ENTIRE spectrum of the plight of the handicapped needs to be studied against the limitless locale of the cultural, religious, social and economic milieu prevalent in different parts of the country. In specific terms, this would mean the widespread poverty, illiteracy, malnutrition, rural economy, unemployment, overpopulation and social mores embedded in such phenomena as superstition, fatalism and the unshakable faith in rebirth. The seventh largest nation in the world, India is next only to China in population. It took India hundreds of years from the dawn of history until the present day to bring her population to today's 684 million; it was just 345 million at the time when we got our Independence.

All these factors have a great bearing on society's attitude towards the handicapped and the will to do something positive for their welfare and rehabilitation. The Hindu religion always stressed the value of charity and philanthropy, but this was in direct conflict with the concept of 'Karma' which believes that handicapped represents retribution for sins committed in the previous birth. It is this nascent philanthropy and religious zeal that brought in its wake the groundswell leading to the creation of voluntary agencies for the welfare of the handicapped.

A planned approach on a rational and scientific basis for the welfare and rehabilitation of the handicapped did not appear until 1945. Here again no government action concerning the services for the disabled was taken until India became free. Before 1947 only voluntary bodies had provided the basic services for the blind, the deaf and dumb, the orthopaedically handicapped and the mentally retarded. The First Plan shifted emphasis from charity to rehabilitation. In the Second Plan emphasis was laid on education and employment with programmes for scholarships for the handicapped students and a plan for setting up a chain of special employment exchanges for the handicapped. Under the Third Plan, the state encouraged development of facilities for vocational training and expansion of employment opportunities for the handicapped and better coordination between public and private organisations to promote these objectives. Though the emphasis tended to vary in the subsequent plans as well, we have formulated a well-defined policy and plan of action for the disabled only during the IYDP.



## THE PLANNED ATTEMPT AT REHABILITATION

Today the situation is several times brighter than it was three decades ago, whether in terms of education, employment, or a more humane attitude towards the disabled, but there is hardly any room for complacency. The task ahead is stupendous and we require enormous resources and political will to carry out definite decisions which alone can put the handicapped alongside the rest of the community.

When India became independent, ambitious plans for a welfare state envisioned a primary role at the policy level for the government with a greater room for action by voluntary agencies. The magnitude of the task made it clear that voluntary effort alone could provide the quality and quantity of services needed for the gigantic task of the welfare and rehabilitation of the handicapped. Thus began the close partnership between the government agencies and the voluntary agencies. Today there are several voluntary agencies getting assistance from government agencies and the Central Social Welfare Board in the various programmes for the handicapped.

The formation of the Board in 1953 was a recognition of the fact that the voluntary organisations had come to stay in many ways. The voluntary agencies enjoyed the prerogative of a certain flexibility of action, willingness to experiment and a close personal touch with the clientele which government agencies do not have.

Most of the national voluntary organisations for the disabled have appeared relatively recently. Only one is a century old, 9 have had their golden jubilee and 17 have celebrated silver jubilee. More than half have their headquarters in Delhi and the rest are located in Bombay, Calcutta and Madras. The Delhi location apparently helps them maintain close contacts with government departments concerned with welfare and other social services.

Much of the financial support for these voluntary organisations comes from a variety of sources like donations, membership of institutions, sales proceeds, government grants, international aid, fund raising campaigns, and affiliation fees from their branches.

There has been a shift in emphasis in the programmes of services offered by different voluntary agencies in the country. The change in emphasis has been from:

1. Social reform to social welfare services;
2. Custodial care to permanent rehabilitation;
3. Institutional services to community welfare services,
4. Special institutions and schools for the handicapped for integration in regular schools;
5. Free services to the charging of token fees; and
6. Curative and treatment services to preventive services.



## SPECIALISED SERVICE

Most of the voluntary agencies, registered under the Society's Registration Act of 1860, offer specialised services for separate categories of the disabled like the blind, the deaf and dumb, the orthopaedically handicapped and the mentally retarded. A mass or group approach is being replaced by a more individualised approach. Agencies are formed increasingly on the national level moving away from a strictly local approach to social problems. There are now more women than men in the field of social welfare; most of these women are well-educated, hailing from middle class or upper middle class families.

To assess the magnitude of the problem we have yet to get the data on the handicapped on the basis of the 1981 census. Till then, we have to bank upon the UN estimate that 10 per cent of the population of every developing country comprise handicapped groups. Accordingly, India has 68.4 million handicapped, an astronomical figure indeed! The number of institutions to serve all categories of handicapped in the country are in the region of 794 (according to an estimate made in 1969). Their break-up is: blind: 284; deaf: 223; orthopaedically handicapped: 154; mentally retarded: 133; total 794.

The Tables on next page give the statewide and citywise break-up of institutions for the handicapped.

Of the 794 institutions, 80 per cent are run by voluntary agencies, only the remaining are run by either the Central Government directly or by the state governments.

## DISTRIBUTION OF THE INSTITUTIONS

The maximum number of institutions for the handicapped are in Maharashtra, followed by Tamil Nadu and Gujarat. This must be attributed to the greater momentum which the social welfare movement has gathered in these three States in contrast to the position obtained in the others. This phenomenon is again highlighted by the fact that Bombay leads with 82 institutions followed by Delhi, Calcutta and Madras. That Delhi has more institutions for the handicapped than Calcutta and Madras has to be explained in the context of it being the capital of India and the fact of it being the headquarters of many national voluntary organisations. In states like Kerala, Maharashtra and Gujarat, there is an even distribution of the voluntary institutions in most of their cities and towns. In the case of West Bengal the bulk of the institutions are to be found in the city of Calcutta.

The rehabilitation services provided by the voluntary agencies include:

1. Medical care which covers diagnosis, surgical treatment and prosthetic and orthopaedic appliances, convalescence facilities, physical



## STATEWISE BREAK-UP OF INSTITUTIONS FOR THE HANDICAPPED

St. No.	State or Union Territory	Blind	Deaf & Dumb	Orthopaedically handicapped	Mentally Retarded	Total
1.	Andhra Pradesh	9	8	8	5	30
2.	Assam	8	2	NA	NA	10
3.	Bihar	10	9	9	2	30
4.	Chandigarh	1	1	NA	3	5
5.	Delhi	16	14	8	13	51
6.	Goa	—	—	1	—	1
7.	Gujarat	34	21	9	14	78
8.	Haryana	8	1	2	1	12
9.	Jammu & Kashmir	4	2	NA	NA	6
10.	Himachal Pradesh	—	—	1	—	1
11.	Karnataka	15	6	10	15	46
12.	Kerala	14	14	17	6	51
13.	Madhya Pradesh	15	16	8	9	48
14.	Maharashtra	52	34	32	27	145
15.	Manipur	1	Nil	Nil	NA	1
16.	Meghalaya	—	1	Nil	NA	1
17.	Mizoram	1	Nil	Nil	NA	1
18.	Nagaland	Nil	Nil	Nil	NA	0
19.	Orissa	3	6	1	NA	10
20.	Pondicherry	3	1	2	NA	6
21.	Punjab	11	5	5	5	26
22.	Rajasthan	7	6	5	1	19
23.	Tamil Nadu	34	24	21	10	89
24.	Tripura	1	Nil	Nil	Nil	1
25.	Uttar Pradesh	28	23	6	7	64
26.	West Bengal	9	29	9	15	53
TOTAL		284	223	154	133	794

## CITYWISE BREAK-UP OF INSTITUTIONS FOR THE HANDICAPPED

1.	Bombay	24	18	14	26	82
2.	Calcutta	5	22	9	9	45
3.	Madras	11	8	8	13	40
4.	Delhi	16	14	8	13	51

and mental therapy.

- Education for the blind, the deaf, the orthopaedically handicapped and the mentally retarded.
- Vocational training including prevocational training in established schools.
- Sheltered employment and open employment in vocational training centres and sheltered workshops.

Though it may not be possible to catalogue all the top good institutions,





a random sampling of the work being done by some of the select institutions could be mentioned here without prejudice to the equally good work being done by the others in the same fields or other fields. Take, for example, the institution for the handicapped children and adults situated at Chandimandir in Haryana State on Chandigarh-Kalka Highway. The institution has an integrated approach to the needs and problems of the orthopaedically handicapped. It provides surgical and medical treatment, occupational therapy and physiotherapy treatment, facilities for academic education, vocational training and rehabilitation. The institution caters to the needs of patients from Haryana, Punjab, Himachal Pradesh, Uttar Pradesh, Delhi, Chandigarh and Rajasthan.

An institution for the mentally retarded in Calcutta has on its panel educationists, psychologists, physicians, physiotherapists, occupational therapists, musicians, craft and weaving teachers. Apart from the curative measures of teaching, vocational training is imparted in trades like clay-modelling, cloth printing, weaving, knitting, doll-making, mat-making, etc.

In the sphere of the welfare of the deaf, the All India Federation of Deaf (AIFD) has done a great deal of spade work and it is the premier organisation for the deaf with 44 state level associations and schools working systematically for the welfare of the deaf. The AIFD is affiliated to the World Federation of the Deaf in Rome which has consultative status with the United Nations and its sister organisations. The Federation has a multipurpose centre in Delhi which seeks to train the deaf in different trades suited to their aptitudes and ability.

#### ATTEMPTS AT SOCIAL INTEGRATION

Similar to the All India Federation of the Deaf, there are other all India organisations working for different groups of handicapped. Special mention may be made here of the National Association for the Blind, Bombay, and the National Federation of the Mentally Retarded. The National Association of the Blind does multifarious activities for the education, training, recreation and social integration of the blind. This is the only organisation which seeks the total rehabilitation of the visually handicapped taking into consideration all aspects of their cultural, social and economic life. The Association is the pioneer organisation which started sending blind children to normal schools where they are taught through specialised equipments and with the help of resource teachers. The basic idea is to promote social integration of the blind with the disabled, helping the able bodied understand the problems and potential of the disabled classmates. It also tells the world that the blind too, along with the other handicapped, can work in any normal situation if given an opportunity. Most of these schools promoting such integrated education are located in Bombay and a few in other major cities. (Similar schools where the deaf children attend normal schools are located



in Delhi and some other states too, thanks to the initiative taken by voluntary agencies.)

Nearly two decades ago in January, 1960, the Association gave a lead to the rest of India by starting the first ever agricultural and rural training centre of the blind at Phansa in Gujarat. It acquired an estate of 240 acres and several other facilities like dairy sheds, irrigation tank, wells, etc. With the help of the Royal Commonwealth Society for the Blind, the Phansa project started training the blind in agriculture, horticulture, animal husbandry, dairy, poultry farming, fish culture and the like. The idea was to train the rural blind in different agro-based pursuits. The blind trainees were encouraged to work independently on all the chores of agricultural operations. The Phansa centre lays great emphasis on resettling the blind. Without socio-economic rehabilitation, the training will lead them nowhere.

Similar to the Phansa project the Ramakrishna Mission in Narendrapur near Calcutta trains the rural blind as an integral part of the main agricultural and rural project for normal trainees. The project promotes integration of the blind in the normal community.

In South India, the Helen Keller International, Madurai, has developed a mobile rehabilitation team which collects the rural blind belonging to a group of villages and trains them in elementary farm occupations and rural jobs. The training enables the blind to help the family on the farm and non-farm jobs. In a country as vast as India, and with a great rural population, the experiments conducted in Phansa, Narendrapur and Madurai need to be emulated in the rest of rural India. In fact, there is a great scope for the rural blind to work as farm hands, or work on orchards or vegetable gardens or engage themselves in animal husbandry, dairy, goat and sheep rearing, cottage industries, running of petty village shops and in food processing industry, to mention a few vocations.

In the field of mental retardation also, there are many institutions for the education and training of the mentally retarded children and adults. At the national level we have the National Federation of the Mentally Retarded. There are several schools for the educable and trainable mentally retarded children, but their number is small and the facilities are available only in the cities and towns. For the orthopaedically handicapped, there are fewer institutions than for the deaf or the blind. For the production of artificial limbs and appliances, voluntary institutions are doing creditable work. Mention may be made here of the Rehabilitation Centre of the Bhagwan Mahaveer Viklang Sahayata Samiti in Jaipur. Here at Jaipur, they make a variety of shoes and legs, all custom made, to suit the orthopaedically handicapped who have to work in a rural background. These artificial legs are not spoiled even if they become wet as they are made of rubber. The treatment and fitting of the limb is free at the centre for all patients, though any one is welcome to give a donation, if he chooses. The Samiti also pays return railway fare to the needy patients. Over 5000 people from different parts of





the country have so far benefited from this project.

Among the metropolitan cities, Bombay can boast of some of the most prestigious associations, organisations and institutions for the disabled. To Bombay goes the credit for pioneering the first experiment in the whole country in integrated education of the blind as early as in June, 1958, when two 11-year old blind boys were enrolled in the New Activity School, a public school in the city, after they had been privately tutored for several months in English braille, both reading and writing, so that they could follow the school lessons easily.

Today for the welfare of blind alone Bombay has a blind men's industrial cooperative producers' society ltd., blind men's working hostel, and an industrial home for blind women, a home for the aging blind, a nursery for the blind, and a workshop for the blind, to mention only a few. Similarly for other categories of handicapped too, there are several agencies that are conducting a wide variety of activities seeking to secure rehabilitation in the field of education, training and employment.

In the ultimate analysis, the total welfare of the handicapped would hinge on the political will we may lend to the momentum already generated by the voluntary sector. We do not seem to have touched even the fringe of the problem compared to the magnitude of the job in hand. More resources have to be mobilised, more purposeful education of the public and the employers on the problems and potential of the handicapped has to be organised, and to crown it all, we have to change our basic attitude towards the disabled. While the voluntary agencies have done their best in their own humble way for the welfare of the disabled, the greatest achievement they have made is the awareness and social awakening, they have been able to create in the community, however small though it may seem.



## The Disabled—Their Problems and Solutions

S.K. Verma and Anil Chawla

THERE ARE no universally agreed definitions for the terms commonly used like 'impairment', 'handicap', 'disability', 'prevention', etc. Despite attempts by WHO, ILO the UN Rehabilitation Unit and other agencies, the drafts for different definitions have not reached a final shape. The reasons are the legal and administrative implications of these terms. The international classification of diseases (the ICD code), deals mainly with the diagnosis and does not cover the health status measurement in the form of ability, etc.

The pattern of development of an illness is seen in the phases as: etiology—pathology—manifestations. On similar pattern the patients' altered social role may be perceived as: impairment—functional limitation—disability.

Each of these need to have clear, well defined definitions with standard methods of quantification. In classifying 'impairment' it will be essential to keep in mind the anatomical, physiological and psychological aspects. In classifying 'functional limitations' it is important to categorise them as short-term or long-term, permanent or reversible, progressive or regressive.

Very few studies have been undertaken to analyse the magnitude and nature of the problems of the handicapped and these lack comparability because different definitions and criteria of disability are used. Most of the quantitative studies deal with estimations of the prevalence of impairment and functional limitations rather than the disability. Some of the figures are over-estimations and others grossly understate the magnitude of the problem.

WHO estimated that 10 per cent of the world population is disabled. Allowing for some miscalculations and double counting, the lowest estimates exceed 8 per cent of the world population. If we apply the same percentage to calculate the number of the disabled in India, it comes to 48 to 60 million. These include the orthopaedically handicapped, the deaf and mute, the blind and visually handicapped, the mentally retarded and mentally ill. There is no evidence at this time that this number will decrease in the near future. On the contrary we have to contend with an increasing number due to following factors: Increase in population; decrease in mortality and increase in morbidity; increase in industrial, agricultural and road accidents; use of forceps and late child bearing; increased survival rate of pre-mature infants; due to better neo-natal care; increased use of irradiation, X rays, etc.



nutritional deficiency; increased incidence of cerebro-vascular and collagen diseases; and increased incidence of congenital diseases.

#### NO LET-UP IN THE GROWTH RATE OF THE DISABLED

It is estimated that as the population increases by about 13 million a year, 1.3 million are added to the number of the disabled. If the present population growth rate continues, it will be increasingly difficult to achieve socio-economic development including the general development of community health care services.

Advancement in medicine and surgery has enhanced the survival rate of certain handicapped who would have died early otherwise, *e.g.*, use of antibiotics in those prone to infections, mongols and those with CNS infections. Modern surgical techniques in the management of hydrocephalus, meningocele and greater obstetrical interference have saved many babies but with physical handicaps, mental handicaps, epilepsy and various other defects. Better neo-natal care has led to increased survival rate of premature infants who have higher incidence of brain damage and congenital defects.

Due to inadequate preventive measures, the number of persons with disability as a result of polio, tuberculosis, trachoma, malaria and leprosy have not decreased. The mortality from gastro-intestinal and respiratory diseases is lower. This also implies that along with the young paralysed, blind and deaf persons, those with severe complicated fractures, severe burns, blindness or mental disturbances (*e.g.*, psychosis, retardation, etc.) will survive and occupy an increasing part of the adult and aged population.

Increase in industrial, agricultural and road accidents have led to an increase in the number of the orthopaedic disabled in the country. Increased urbanisation with rapid industrialisation is also associated with a rise in the incidence of neurosis, psycho-somatic disorders, alcoholism and drug abuse.

Fifty to sixty per cent of all mongols are last born; maldevelopment of CNS occurs; more with advancing maternal age. Food shortages, leading to malnutrition and anaemias in mothers, result in increased incidence in pre-term births, early rickets and mental retardation in babies.

Narcotics, greater use of anaesthetics, sedatives and other drugs have led to an increase in the incidence of congenital amputees.

Till such time that we are able to prevent many of the above factors by early and timely care, the problem of the handicapped is bound to increase.

#### DISABILITY AND SOCIO-ECONOMIC DISADVANTAGES

In our country there is a close association between disability and socio-economic disadvantages, *e.g.*, poverty, lack of education and job opportunity, working conditions, geographical isolation, social prejudices built into



the structure of society, and religious factors. The highest incidence of disability is found among the underprivileged. Thus no one single intervention (such as improved medical services) would solve these complex multifaceted problems of the disabled.

A handicapped individual has a basic right to human decency and to a life of productivity and fulfilment whether his handicap is mild or severe, single or multiple, incurred at birth or later in life, whether he lives in an urban or rural environment or whether his family has income or is poor. Special kinds of treatment, education, training, welfare support and other rehabilitation services must be provided which are appropriate to the handicapped person's needs, if he is to benefit from this basic right.

*Provision of Aids to the Disabled :* One of the main requirements of a disabled person is to get over fully or partially the disadvantages that occur to him because of his disability. The disadvantages could be reduced/eliminated by either medical care and/or by a provision of an artificial limb/wheelchair/hearing aid/visual aids, etc. Since a very large number of the disabled, needing aid are from economically weaker sections of the society, the provision of such aids should statutorily be made free or subsidised to bring its acquisition within the means of the persons who need them. The manufacturing and fabrication facilities for aids should be augmented, so that the waiting time for artificial limbs and calipers be reduced.

### SERVICES TO THE DISABLED

There is great need to take this service to the rural areas by holding camps where the disabled could be provided with prosthetic aids.

*Education:* All handicapped children should be provided with facilities to attend schools. Separate sections should be opened in ordinary schools for the education of the blind and the deaf-mute children. Adequate and subsidised transport should be provided to the disabled to attend schools and colleges.

To facilitate access to class rooms, toilets and places of recreation, architectural barriers should be removed. Ramps should be provided at the entrance of the building/classroom. Doors or rooms/toilets should be wide enough to admit a wheelchair. As far as possible the classes for the disabled should be on the ground floor.

*Vocational Training and Employment:* It is necessary to impart employment oriented training to the disabled in consultation with the local industry so that soon after their training, it should be possible to provide them employment. It is necessary that a lot more attention be paid to the furtherance of the programmes, leading not only to the paid employment but also to self employment, rural employment, employment in production units, in home workers scheme, in vending stands, in independent professions, etc. The existing community resources should be fully availed of and geared for



furthering the employment and economic resettlement of the disabled. In particular, the Khadi and Village Industries Commission and small scale and cottage industries department should be motivated to extend the benefit of their existing approved schemes to the disabled. Instructions have to be issued by the concerned ministries to the officers heading such schemes to arrange for the employment of the disabled by making suitable provisions in their policies and procedures.

*Pension Scheme:* Severely handicapped persons who are not in a position to earn their livelihood could be covered under this scheme. Those with more than 75 per cent disability may be considered for grant of pension.



# **Transport Problems of the Disabled : A Study of the Rehabus Scheme in Hong Kong**

**Dorothy Chan**

**T**HIS PAPER is an attempt to evaluate the very first experimental project in Hong Kong that aims to provide a special service for the disabled in solving their transport problems. The paper begins by outlining the nature of the problem, *i.e.*, what difficulties are encountered by the disabled in respect of transport facilities, and then moves on to trace the historical development of the public policy in Hong Kong that deals with the transport problems of the disabled which leads to the inception of the rehabus scheme. This is followed by a brief description of this experimental project, its aims, characteristics, and development up to date. Before proceeding to evaluate the rehabus scheme, I shall briefly discuss the need identification aspect of this experiment, providing some insight into the background against which the experimental project takes shape. The full evaluation of the rehabus scheme consists of discussions on the input and output of the experiment, the extent to which it has achieved its stated objectives, in terms of effectiveness and finally the benefits it brings to the society as a whole.

## **THE NATURE OF THE PROBLEM**

Disabled people with restricted mobility can generally be grouped into two categories, namely, the ambulant and the wheelchair disabled. Many ambulant disabled in crutches or calipers are capable of using public transport such as buses and trams, but they usually encounter some difficulties as the buses are not designed to cater for their special needs. Such difficulties are especially apparent during rush hours. The wheelchair disabled are much more limited in their choice of transport and the options open to them are only private cars or taxis. Difficulties in transport present such enormous problem to the disabled that isolation, frustration, and unemployment are very often the dire consequences.

The goal of rehabilitation is to help the disabled to attain and maintain the highest possible function in all aspects of life. It is the professed objective of rehabilitation services to assist the disabled, as far as possible, to become



independent and productive members of society so that, instead of being segregated, they will be integrated into the community. Confronting the transport problems as mentioned, rehabilitation workers often find that even though the disabled person has been fully rehabilitated medically, educationally, or vocationally, he may still not be able to work and live as everybody does simply because he cannot leave his home for lack of suitable transport facilities. The entire effort of both himself and the rehabilitation team will then be fruitless for even after having gone through the various stages of rehabilitation successfully, he still cannot live an independent life. Transport seems to be the major problem among others such as access, housing, employment, etc., that need to be solved in order that the disabled can be successfully integrated into society.

### EVOLUTION OF THE PUBLIC POLICY

The very first time when transport for the disabled became an item in a policy paper of government was in 1973 when the five year plan on social welfare development, published in pursuant to the white paper on social welfare in Hong Kong entitled 'The Way Ahead' mentioned categorically that transport for the disabled should be an area of concern for the planners. This item was taken up at the first annual review of the five year plan during that year and a joint working party between the Hong Kong Council of Social Service and the Social Welfare Department was established to study the transportation needs of the disabled. This working party formulated a proposal for the establishment of a minibus scheme for the disabled in Hong Kong. This proposal was the forerunner of the present rehabus scheme.

Even though this joint working party recommended a minibus scheme, it would not be surprising that such a proposal, among many others considered at the annual review of the five year plan, would be left alone for years before acted upon. However, there was a very important event that spurred this project ahead of many others which might have logically been placed on higher priority of the action list.

This event was the decision of the government to build the mass transit railway (MTR) in Hong Kong. Ever since the government announced the MTR project, there was strong representation from the voluntary sector coordinated under the joint council for the physically and mentally disabled, Hong Kong, emphasising the need to make the MTR accessible to the disabled, particularly the wheelchair-bound. Lobbying activities of the joint council, included seminars, press releases, press conferences, meetings with UMELCO members, open letters to the MTR corporation, etc. However, despite such concerted efforts and extensive arguments, government finally turned down the proposal of making the MTR accessible to the wheelchair disabled. On July 15, 1974 in a letter addressed to the chairman of the joint





council, the UMELCO office formally declined such a proposal on the ground of costs, safety, and structural problems. However, it did say in the letter that UMELCO would ask "government to consider whether it is possible to organise special transport services (travelling from door to door) for the use of particular groups of handicapped persons who are unable to travel by other forms of private or public transport". The MTR issue finally died its unnatural death in November 1974 when the director of public works announced in the Legislative Council that the MTR would not be made accessible to the wheelchair users. But at the same time he also pointed out that the most practicable solution to the transport problems of the disabled was by improving surface transport, thus echoing the UMELCO reply delivered 4 months earlier.

In fact in September 1974 a government working group on transport for the disabled had already been established under the chairmanship of the Commissioner for Transport with the following terms of reference: "To recommend to government what steps might be taken to provide surface transport more suited to the needs of the disabled." I have little doubt that the primary purpose of this working group was to take the heat off the MTR issue, with promises for a brighter future in the provision of surface transport for the disabled. But it was this very working group that produced a thorough and comprehensive report, embodying the entire policy of providing better transport facilities for the disabled in Hong Kong.

The government working group produced its report in March 1975 which included 16 recommendations, covering all aspects of the transportation needs of the disabled. Among these recommendations was the 'minibus scheme for the disabled', mentioned earlier, being a product of the five year plan review.

In October 1977, the white paper on rehabilitation, which is the government's policy and plan for the next 10 years for the development of rehabilitation services in Hong Kong, was published. In para 6.14 the importance of transport facilities as recommended by the government's working group was emphasised, and the experimental minibus scheme for the disabled was specifically mentioned as a new way of dealing with the problem.

Subsequent to the publication of the white paper, a rehabilitation development coordinating committee (RDCC) was established to oversee and coordinate the implementation of the recommendations in the white paper, and several sub-committees under the RDCC were also organised. One of them was a sub-committee on transport and access for the disabled. At this stage it was clear that the transportation needs of the disabled would not be overlooked, and the policy recommendations evolved through the years would be implemented in a coordinated manner.

As such, one can say that the MTR issue has indirectly expedited the process of developing an overall comprehensive policy on the provision of transport services for the disabled in Hong Kong, with much of the ground





work having been done in 1974 and 1975 by the two working groups mentioned, and finally given official recognition in the white paper. With the evolution of this policy, the rehabus scheme for the disabled came into existence in 1977 as a new programme to meet an age-long challenge.

#### OPERATION AND DEVELOPMENT OF THE REHABUS SCHEME FOR THE DISABLED

##### *Aims and Operational Objectives*

The rehabus scheme (originally the minibus scheme for the disabled) is aimed at testing the feasibility of an exclusive fixed route/scheduled minibus service in meeting the transport needs of the disabled at a reasonable cost. Under this aim, there are three operational objectives as stated in the annual report of the joint council:

1. To relieve the transport difficulties of those disabled people who were already working, studying, or seeking treatment before the operation of the scheme. These transport difficulties may include the physical difficulty of getting on buses, going to work in time, or the high cost of private transport/taxis.
2. To provide special transport service to and from work so that those who have not been working before can now take up gainful employment.
3. To test the demand for transport services among the disabled through the operation of the scheme.

##### *Target Population*

The target population of the scheme is those disabled who are functionally impaired to such an extent that they find it difficult or impossible to use such common public transport facilities as buses and trams.

##### *Mode of Operation*

The scheme is basically a door to door service operated on a fixed schedule and fixed route basis. When applications are received, a route and a time-table of service will be worked out to meet the needs of as many applicants as possible along the route. The successful applicants will be notified of the time that they have to go downstairs to wait for the bus. The bus will, according to the predetermined route, at the scheduled time, pick up and set down passengers on the way twice daily, once in the morning and once in the afternoon to fulfil the purpose of transporting disabled people to and from work or school. It is worth noting that the routes and schedules are adjusted each time a passenger withdraws and a new one joins in. This is necessary as the routes and schedules are planned



according to the needs of the passengers. Originally the fare was \$0.5 per person per trip. It was raised to \$1.00 in April 1979.

#### *Development of the Scheme*

The scheme started off in the name of 'minibus scheme for the disabled' under the auspices of the joint council. As an experiment, the service was first confined to the East Kowloon area on the ground that there are quite a number of disabled persons known to be living in this area and that there are both distinct residential and industrial areas within East Kowloon. Application forms were sent to all possible sources of referral such as social welfare agencies, CDOs, social centres, etc., and publicity was organised. The service began in February 1977 with two minibuses (7-seaters) carrying a total of 17 regular passengers during the week days for the first 16 months. The service proved to be popular and at the end of the first experimental period, there were over 80 disabled persons on the waiting list. In order that the service could be established on a permanent basis and expanded to cope with the increasing demand, the Hong Kong Society for Rehabilitation formally took over both the operation and administration of the entire service as from June 1978. The service was re-named the 'rehabus scheme for the disabled' and a special committee called the rehabus committee was formed to oversee and supervise the running of the service, employing a full time transport manager. The service was expanded to four routes with four 7-seater minibuses in July 1978 carrying 43 regular passengers everyday. The routes were extended beyond East Kowloon, covering the Hong Kong side too. In December 1978, two more 7-seater minibuses were added to the service making it a total of six routes catering for 74 passengers. Later on two more buses were added and the fleet now comprises minibuses with six on the Kowloon side and three on the Hong Kong side, carrying 108 passengers. The day to day operation of the rehabus service is controlled by the manager who is responsible for route scheduling, receiving telephone orders, supervision of drivers, collection of revenue, preparation of statement of accounts, servicing and maintenance of vehicles and liaison with passengers for feedback.

#### *Service Characteristics*

The main features of the rehabus scheme can be summarised under the following headings:

*Directness of Route:* The rehabus service is characterised by route deviations in order to provide a door-to-door service for the disabled.

*Structuring of Routes:* The rehabus will not go to whatever destinations the traveller wishes on the spot. The routes are pre-determined based on the origins and destinations of the selected passengers.

*Public Service Aspect:* The rehabus service is a public service as distinct from a strictly private service such as the private automobile. The service,



however, is specifically for a special group of passengers made available on a pre-arranged basis.

*Method of Requesting Service:* The service will not response to 'hail-a-ride' as a means of access to the mode. Service will only be made available by prior arrangements.

*Reliability of Service:* An important service characteristic of the rebus is the ability to use certain prohibited roads such as the bus lanes and restricted places such as urban clearway zones to gain access or to pick up the disabled passengers. This enables the provision of a door-to-door service which to a certain extent is free from restrictions, and from some notorious traffic congestion spots, thus ensuring reliability of service.

*Comfort:* The rebus provides a comfortable service with guaranteed seats for the passengers and a door-to-door service. Rebus drivers also assist the disabled persons in boarding the buses where necessary.

*Peak Hour Operation:* The main operating hours are between 7 a.m. and 10 a.m. and 3.30 p.m. and 7.30 p.m. The majority of the peak hour travellers use the service to work and some to schools and hence producing distinct peak periods.

*Ancillary Service:* For the off-peak periods in the weekdays and Sundays/public holidays, a service called 'dial-a-ride' is provided for disabled persons for other purposes such as recreation, shopping, visits, or medical treatment. This is arranged on a prebooked basis and is more like chartering a service rather than the usual dial-a-ride service which is immediately responsive to telephone orders received.

## NEED IDENTIFICATION

Before proceeding to evaluate the rebus scheme itself, I think it is important to ask a basic question, *i.e.*, is there a need for the provision of such a special service for the disabled?

Theoretically, it is sound argument that transport is the key to the integration process of the disabled. It is the link to nearly every activity of those disabled with restricted mobility, *e.g.*, work, school, medical treatment, recreation, sports, leisure, etc. Without the assistance of such facilities, one can hardly expect the rehabilitation process to be complete. But what about the statistical support to such an argument? How many disabled are in need of such special transport facilities? How can one be convinced about the actual and future utilisation of such services?

In the absence of a comprehensive survey specifically conducted to identify the transportation needs of the disabled, the best method is to use all existing figures and statistics to come up with an 'educated guess'. The 1971 census can only be of a little help as a start. It located only 14,588 (only 0.36 per cent of the total population at that time) disabled persons in Hong Kong, among whom about 4,177 would probably be in need of special



transport services (823 paraplegics, 1956 hemiplegics, and 2,398 loss of lower limbs). The commissioner of census and statistics, nevertheless, did admit that the result of the census as to the disabled population was unreliable, because of many practical and procedural difficulties. In 1973 a comprehensive transport study was carried out for government by Messrs. Wilbur Smith & Associates and it included questions on the disabled. Disabled people were operationally classified by reference to their mobility. The results showed that there were 15,200 disabled people in Hong Kong (0.4 per cent of the total population) and about 4,600 of them were either wheelchair-bound or could move about only with artificial assistance, thus were probably in need of a special transport service. The results of this study correlated quite closely with the 1971 census and as such it was not surprising that the following comment appeared at the end of that report: "Due to the small number of disabled persons sampled (393 only), reservations should be made about use of the information gathered."

The above figures were seriously challenged by the joint council which quoted the internationally recognised figure that in any population there is bound to be at least 7 per cent of persons suffering from some kind of disability. On this calculation, the total number of disabled people in Hong Kong should be 280,000. This argument received partial support in the white paper, and in the programme plan for rehabilitation (*i.e.*, the 10 year plan putting the policies in the white paper into practice) the group of physically disabled *alone* was estimated to be around 15,000 in mid-1979. In other words, the number of disabled people who are likely to be in 'comparative' need of special transport service has 'increased' on paper tremendously.

On the other hand, the need for better transport facilities had been expressed many times throughout the years by both the disabled themselves and by the rehabilitation personnel working with them everyday. Notable examples were the symposium on transport for the disabled held in March 1974, the seminar on access and transport in 1975, and the various reporting back seminars on conferences held by the joint council during 1976, 1977 and 1978. The need was 'felt' and indeed was among the priority action area of the voluntary agencies under the joint council.

Perhaps the most dramatic illustration of the actual need for special transport service was the rehabus scheme itself. The scheme carried out 2 surveys (in the form of invitation for applications to become passengers to the scheme), one before the operation began in December 1977, one near the end of its first year of operation. For the first survey which was carried out mainly in the East Kowloon area, 56 applications were received. During its first few months of operation there were another 26 applications. The second survey extended its catchment area to the whole of Hong Kong and Kowloon and 201 disabled applied for the service. These figures excluded those who, although having submitted applications, were not eligible



for the service because they were not so restricted in mobility. There was, as such, a total of 283 applicants for the first year of operation, a figure far beyond the capacity of the scheme.

All the above information and discussion are agreeable to the general proposition that transport for the disabled is an area needing quick and effective action. An important conclusion I can draw, especially from the figures quoted, is that the number of disabled people with mobility difficulties is not likely to be overwhelmingly large, and so it may not be necessary to radically redesign the whole public transport system such as buses and trams to make them available for all disabled persons. Proposals to install hydraulic lifts on buses would be unnecessary, apart from being practically and financially not viable. On this basis, I can safely say that the rehasub scheme is the right step towards relieving the transport problems of the disabled.

#### EVALUATION OF THE REHABUS SCHEME FOR THE DISABLED

The essence of evaluation is the assessment of the outcome of a programme, *i.e.*, what happened that would not have happened in its absence. It embraces basically two concepts—that of ‘effectiveness’ and ‘benefits’. Effectiveness measures the extent to which the objective is attained and whether they can be better achieved in alternative programmes. By benefits one means those impacts or consequences that one regards as favourable or positive, bearing in mind the objectives as opposed to the costs. Evaluation is carried out to provide information either to policy makers on the cost and effects of their programmes, and to aid in the efficient allocation of resources, or to programme managers to help them in the effective management of the programmes, or both. My evaluation of the rehasub scheme is more for the former purpose, *i.e.*, to determine the effectiveness of the programme in meeting its professed objectives, thereby assisting resources allocation decisions. This evaluated exercise is formulated to provide answers to questions such as whether the scheme is successful in attaining its objectives, whether it meets the actual transportation needs of the disabled, and whether further resources should be devoted to expanding the scheme.

In the following paragraphs I shall evaluate the rehasub scheme under the two important aspects of ‘effectiveness’ and ‘benefits’ to determine the extent to which it has achieved its objectives. But before going into the actual evaluation, it is prerequisite that I should set out in concrete terms the input and output of the scheme in order to support the ensuing discussion on evaluation.

**INPUT:** The two important elements of input are ‘manpower’ and ‘finance’. As far as manpower is concerned, the rehasub scheme is supervised and monitored by a rehasub committee under the Hong Kong Society for Rehabilitation which has 8 members. All committee members are volunteers



or in representative capacity (e.g., representative of the transport department) and so the committee does not impose any financial burden on the programme. The operation of the scheme is coordinated and organised by a full time salaried transport manager and all drivers are also paid staff. Their salaries are included in the following paragraph on finance.

The recurrent expenditure of the scheme is supported by the community chest under its pilot project fund for 3 years beginning June, 1978. Capital expenses for the purchase of buses are mainly underwritten by a donation of the Royal Hong Kong Jockey Club (9 buses for the same period) and some service clubs, e.g., lions club. The operational cost which includes salaries, fuel, repair, insurance, licence fees, and other miscellaneous items of expenditure was \$15,508 in April, 1979 (6 buses carrying 106 passengers performing altogether 2,326 man-trips); \$18,520 in October, 1979 (8 buses carrying 142 passengers performing altogether 3,702 man-trips); and \$2,3751 in March 1980 (9 buses carrying 172 passengers performing altogether 3,895 man-trips).

*OUTPUT: (a) Regular passengers:* When the scheme first started in February 1977, there were 17 regular passengers with 2 buses in operation. The number of passengers then increased with the addition of more buses in the following stages:

	<i>No. of buses</i>	<i>No. of Regular Passengers</i>
July 1978	4	43
April 1979	6	82
Oct. 1979	8	96
Mar. 1980	9	107

When the scheme first started, there were 7 wheelchair-bound among the 17 passengers, the rest were all on crutches or calipers. Using the same dates as above, the analysis of the passengers according to their disability is as follows:

	<i>Wheelchair</i>	<i>Crutches</i>	<i>Blind</i>	<i>Mentally Retarded</i>	<i>Others</i>	<i>Total</i>
July 1978	8	23	3	4	5	43
April 1979	11	33	10	21	8	83
Oct. 1979	8	41	7	33	5	94
Mar. 1980	11	41	9	40	6	107

*(b) Man-trips performed:* Closely related to the number of passengers is the number of man-trips performed every month. It is using this figure against the operational cost that the cost per man-trip can be calculated.



The man-trips performed, using again the quoted dates, are as follows:

	<i>No. of Man-trips</i>
July 1978	964
April 1979	2326
Oct. 1979	3702
Mar. 1980	3895

As for the purposes of the man-trips, the following table is illustrative:

<i>Months</i>	<i>Employment</i>	<i>Study/ Training</i>	<i>*Medical Treatment</i>	<i>*Re- creation/ shopping</i>	<i>*Others</i>	<i>Total</i>
July 1978	(information not available)					
April 1979	1,559	485	11	81	190	2,326
Oct. 1979	2,552	673	18	362	97	3,702
March 1980	2,483	987	3	257	165	3,845

\*Dial-a-ride service.

(c) *Waiting-list*: When the H.K. Society for Rehabilitation took over the scheme from the joint council in June 1978, there were nearly 200 disabled people on the waiting list. As the scheme expanded to absorb more applicants, the number on the waiting list dropped gradually. In April 1979 the number on the waiting list was 101, Oct. 1979 it was 120 and in March 1980 it was 106. Accordingly, for the past 12 months there were on the average 112 disabled people on the line awaiting to be accepted as a passenger.

(d) *Route coverage*: The beginning two routes were mainly in the East Kowloon area, one starting from Lam Tin to Lok Fu, the other starting from Tai Hang Tung to Kwun Tong then finally back to Lok Fu. At present the nine routes have extended far beyond the original East Kowloon area and cover the main traffic corridors of Hong Kong as well as many parts of Kowloon. There are 22 routes running mainly within the East Kowloon, *i.e.*, from Kwun Tong in the East to Lok Fu in the West. Two other routes start from East Kowloon but one terminates in Hung Num and the other in Pak Tin. Another route starts from Tsz Wan Shan, goes to Tsim Sha Tsui and then back to Kwun Tong through Ho Man Tin. One other route starts from a point completely out of East Kowloon—from Kwai Fong Estate, through Lei Muk Shu, Mei Foo Sun Chuen, Sham Shiu Po than to East Kowloon, terminating in Yau Tong, probably the longest route. There are three routes on the Hong Kong side, linking Wan Chai and Shauiwan, Western District and Star Ferry, and finally Aberdeen North Point and Central.





(e) *Dial-a-ride service*: Besides the scheduled routes, a dial-a-ride service as mentioned, was established for irregular trips during off-peak hours for leisure, shopping, or medical treatment, etc. The charges are based on \$7.50 per hour and \$0.32 per mile to cover the cost of overtime wages for the driver, and fuel cost. Many voluntary agencies used the service on Saturday, Sundays and off-peak hours on weekdays to carry their clients for the above mentioned purposes, e.g., during the month of March 1980 the number of man-trips performed by this service amounted to 425.

### EFFECTIVENESS

Effectiveness refers to a programme's performance in the light of its objectives. In measuring effectiveness one must look at the question whether the programme is producing the desired kinds of result, comparing actual accomplishments with standards of what is expected of the programme. It involves the identification and measurement of physical or other changes in the environment that are attributable to the programme. The primary concern of measuring effectiveness is thus not whether the programme is being operated as planned, but whether it is producing the intended effects in the environment. In measuring the effects of the rehabus service, it is therefore necessary to look in depth into the number and characteristics of passengers, the man-trips performed and their nature, the impact of the service on the passengers, the coverage of the routings in providing a door-to-door service, the cost in running the scheme and its impact on the discovery of needs of the disabled. I shall examine these aspects bearing in mind particularly the objectives of the scheme.

#### *The Passengers*

With the increase from 2 minibuses in February 1977 carrying 17 passengers to the present 9 minibuses carrying 107 passengers, it can be seen that the scheme is not only increasing its capacity, but more importantly it has also multiplied its efficiency in route and schedule arrangements to take in more passengers and to make fuller utilisation of the buses. Bearing in mind that the minibuses are 7-seaters, the 2 buses at the beginning carried on the average 8.5 regular passengers per bus per day. According to the latest figures, the buses are carrying averagely 12 regular passengers per bus. Therefore there is marked improvement in the effective management of resources available to serve the greatest number of people, although I have no data or recognised standard to show whether this figure of 12 passengers per bus is already the optimum figure in an operation of this nature.

On the other hand, there were 106 on the waiting list in March 1980. On the assumption that they will all qualify for the scheme in every way, the rehabus service is thus only able to cope with 50 per cent of those in need. It can, however, be argued that with the addition of more buses they





can all be catered for. I doubt if this proposition can stand because already in the report of the joint council in October, 1977, about 6 months after the inception of the scheme, it was pointed out that the scheme would not be helpful to those whose place of work was far from home, or falling outside the normal routing of the scheme, or in some rather remote areas. It also mentioned that even though the disabled was within the area of operation, he would still be denied of the service if his time to travel differed from that of the majority passengers. Therefore, these limitations may significantly reduce the number of disabled people being actually able to make use of the service.

Perhaps a more reliable indicator is the comparison between the 'pre and post' rehabus situation of the passengers. Such information is not available for the period after the H.K. Society for Rehabilitation took over the scheme, but a detailed analysis of 15 passengers was provided in a report at the end of the first 6 months of operation under the joint council:

<i>Wheelchair Bound</i>	<i>Pre-Rehabus</i>	<i>After Becoming a Passenger</i>
Unemployed	7	0
Employed	0	7
<i>Those Using Crutches</i>		
Unemployed	0	0
Employed	7	7
Studying	1	1

For the 8 disabled using crutches, their mode of transport prior to operation of the Rehabus service was:

<i>Mode of Transport</i>	<i>No.</i>
Taxi/Pak Pai	2
Buses, minibuses (but with difficulty)	6
	<hr/>
	8
	<hr/>

It can be seen from the above data that the rehabus was undoubtedly the key to employment of the wheelchair disabled. Without this special service, they would not be able to work at all. For those on crutches or calipers, they would save a lot of travelling expenses if they used to go by taxis or pak-pai, and for others they acquired a comfortable and reliable form of transport during the rush hours. The value of the rehabus service is particularly seen on rainy days when the disabled will face enormous frustrations. I think this is a most illustrative example of the effectiveness of the scheme. Unfortunately



such data is not available for the rest of the operation period but I would not be wrong to presume that for the wheelchair users, the rehabus scheme is the major reason, if not the only one, for them being able to acquire and retain gainful employment.

Another good example is that during the initial experimental period, the bus broke down for 2 days in October 1977 and a substitute bus could not be found. The 2 wheelchair passengers were unable to go to work at all. Three of those on crutches took taxis but they had to wait for at least 15 minutes in getting one. One of them was late for one hour because he failed to get a taxi in time. The other passengers used buses but they had to go for the bus much earlier than usual in order to avoid the rush. As such, the value of the scheme can be vividly demonstrated by this rather unfortunate incident.

There is also one aspect concerning the passengers that needs to be examined and that is whether the rehabus scheme is helping those who are within the originally planned target population. Basically, no one will dispute that the scheme is for those disabled who find it impossible or difficult to use public transport such as buses and trams. But there is also little doubt that the primary target group is the wheelchair-bound and those with great mobility difficulty even on crutches and calipers. For the two buses at the inception of the scheme, the wheelchair disabled amounted to 47 per cent and those on crutches/calipers 53 per cent of the total number of passengers. This can be compared with the percentage (I calculate) from the March 1980 monthly report.

	<i>Wheelchair</i>	<i>Crutches</i>	<i>Blind</i>	<i>Mentally Retarded</i>	<i>Others</i>	<i>Total</i>
Number	11	41	9	40	6	107
Per cent	10	39	8	38	6	100

There is quite a big drop in the percentage of the wheelchair disabled among the passengers. On the other hand, the mentally retarded is the second largest group of passengers. I have some doubts on this change of passenger structure because for most of the mildly and moderately retarded, they should be able to use buses and public light buses. For the younger ones who are unable to travel alone, they should be catered for by their own school buses.

Upon closer examination, it is found that the mentally retarded passengers are mainly those moderately retarded attending training centres. It leads me to think that if their number continues to grow, the rehabus scheme may become a subsidiary transport service for the mentally retarded training centres, similar to school buses but different in that the driver provides more assistance to the passengers.



Although they may in actual fact be in need of transport service of some kind, their using the rehabus service in growing numbers may suggest that the scheme is deviating slightly from its original objective, whether for practical or other reasons.

### *The Purpose of Trips Performed*

In the foregoing paragraph on output, the number and nature of man-trips performed have been tabulated. It can be seen that the trips for medical treatment, recreation and others are all from the dial-a-ride service. The regular passengers are all using the service to and from work or school. It is interesting to compare the analysis of man-trips performed in the following table:

<i>Analysis of man-trip</i>	<i>April 1979</i>	<i>March 1980</i>
Employment	1,559	2,483
Study/Training	485	987

The growth rate of trips for study/training far exceeds that for employment. This corroborates the discussion earlier that some mentally retarded children are using the service for travelling to and from schools/training centres. Although on the one hand these figures confirm that the scheme is providing assistance to the disabled, as originally planned, *i.e.*, in their travel to and from work or school, there is a growing danger, as explained, that the service might become a subsidiary school bus service.

### *Costs*

Reading over the monthly reports of the scheme and calculating the cost per man-trip, I find that the average cost is \$6.5 per man-trip from mid 1979 to March 1980. The range is from £5.00 to \$8.00 depending on the number of trips made and the mileage performed and the number of holidays in that month. The cost per man-trip from July 1978 to June 1979 was \$7.16. As such the cost per man-trip has dropped about 60 cents with the increase from 6 buses to 9 buses. Although I cannot say whether this figure \$6.5 per man-trip is a reasonable cost for an operation of this nature, I can safely assume that the cost can be reduced further with the addition of more buses as administrative costs and other overheads will remain more or less at the same level.

The more potent question is whether the same objective can be achieved by an alternative method but at cheaper cost. A good comparison can be made with taxis which is a personalised form of transport, door-to-door, and provides comfortable travel. Calculating from the monthly report of the rehabus scheme of March 1980, the average mileage for each man-trip performed was 3.05 miles for March and 3.4 miles for February 1980. If I take it that the



average mileage per man-trip is 3.2, then if the disabled person takes a taxi, he will have to pay \$8. As such, the rehabus service is cheaper in terms of costs as its operational cost is only \$6.5. Although one can argue that taxis are more comfortable and more flexible, one must bear in mind the following advantages of the rehabus scheme over taxis in meeting the special needs of the passengers:

- (a) taxis are not always available especially in wet days,
- (b) the drivers are usually less helpful than the more experienced rehabus drivers, e.g., in helping to fold up the wheelchair or helping the disabled in getting into the vehicle;
- (c) the taxis do not have the privilege of the rehabus in picking up or setting off passengers in restricted areas. So for some cases even taxis cannot provide a door-to-door service.

#### *Impact of the Scheme*

Bearing in mind that one of the objectives of the scheme is to test the demand for transport service among the disabled, it is necessary to look at the impact of the scheme in this respect. As mentioned in earlier discussions, the two surveys on demand conducted by the joint council resulted in 283 applications and throughout the past year, there were around 110 on the waiting lists. Although these are small numbers comparing with the estimated number of disabled people who may be in need of assistance in transport as discussed under the earlier section of 'identification of need', I am of the opinion that the scheme has uncovered an area of need which may not be easily identified by other methods. By providing a service, the scheme has helped to spur many disabled people into action, therefore it can be said that the service has created a demand by itself. It is interesting to note from the report of the rehabus division officer of the joint council that in the first few months of running the scheme, the officer actually received quite a number of requests from disabled people independent of or in addition to their need for transport services.

New needs for other services were identified and referrals were made to welfare agencies and government departments. This is a positive byproduct of the scheme which is not anticipated in the original planning. But such unintended result is indicative of the trust and confidence that disabled people have in the service and its popularity.

Also the supportive attitudes of funding sources such as the community chest and the jockey club all help to demonstrate the impact of positive publicity and popularity of the scheme as a new social welfare project. From these evidence I think the scheme has actually achieved more than its basic objective in this respect.



## BENEFITS

In examining the benefits derived from the scheme, one would seek to investigate the full range of impacts. As benefit measures for this scheme, I would look for outcomes that move towards specified objectives representing a gain to society. They may represent a change from the present conditions for the better or the maintenance of conditions which would, but for the programme implementation, be expected to deteriorate.

### *Gainful Employment for the Previously Unemployed*

The most significant contribution of the rebus scheme is its assistance given to most of the wheelchair passengers in finding and retaining gainful employment. Many wheelchair disabled are unable to work not because of the limitation of their physical ability but the lack of transport facilities to ensure that they can go from home to work and can go there on time everyday. When the scheme first came into being, 7 wheelchair persons previously unemployed were able to go back to work by taking the rebus everyday. Although subsequent figures in similar cases were unavailable, it can be assumed that as long as the scheme serves its purpose of providing convenient and reliable transport, this effect will always continue.

### *Relief of Difficulties and Sufferings*

For those who are already working prior to using the rebus service, this service provides a comfortable and reliable form of transport that they can be freed from the physical hardship of 'fighting to get on buses', uncomfortable travel aggravated by their physical disability and worries of chaotic traffic on rainy days. The relief from these difficulties for this group of passengers as a result of the rebus service is of enormous value to helping the disable to become as independent as possible both socially and economically.

### *Feeling of Confidence and Usefulness of the Disabled*

The natural and logical consequence of the above positive effects of the scheme is the increase of confidence, self esteem and feeling of usefulness among the disabled benefiting from this service. They are now more prepared to convince the public to stop looking upon them as mere welfare recipients. They should be regarded as potential work force and independent wage-earners. They are now more in a position to shake off the stigma of being dependents of society, segregated from other members of the community; instead they can convincingly assume new roles as independent citizens making contributions in various ways. Thus the social benefits that can be derived from the scheme are enormous. Although the scheme serves only a small number of disabled, the demonstrative effect is impressive.

### *Completion of the Rehabilitation Process*

The combined result of the social and economic benefits derived from



the scheme is the completion of the rehabilitation process—when the disabled is successfully integrated into the society as a contributing and independent member. Unless this is achieved, all resources previously devoted to rehabilitation of the disabled medically, educationally or vocationally will be a complete waste. Transportation provides the missing link in many attempts to complete the rehabilitation process and the rehabus scheme in turn plays an effective role in getting the problem of transportation resolved.

### CONCLUSION

Completing this exercise of evaluating the rebus scheme of the disabled, I have little doubt that the service is playing a vital part in meeting the dire needs of many disabled people who face a lot of problems arising from the lack of suitable transport facilities. I am also convinced that as an experiment the scheme has achieved the objectives as planned and successfully demonstrated that this fixed route and fixed schedule special service can be run at a reasonable cost.

However, it is also through this essential exercise that I become convinced that although being a right step towards the right direction, the rebus scheme is not and can never be regarded as the only solution to the transport problem of the disabled in view of its limitations and the relatively small number of passengers that it can serve even with all conceivable expansion. For many disabled with less severe disability or who are unable to make use of the service for other reasons, other methods to assist them must be contemplated. Specially arranged radio-taxi system, better design for buses and trams, a transport subsidy payable in cash, etc., are perhaps relevant in helping to solve their multi-faceted transport problems.



## **Education and Care of the Mentally Retarded\***

**Anima Sen**

**E**DUCATION OF the mentally retarded was not a matter of much interest anywhere in the world until the early 19th century. It was a landmark in history of education when Jean Mark Itard undertook to educate Victor, the wild boy of Aveyron, in 1801. He tried to give sense training to Victor along with emphasis on the establishment of social, communications, and problem-solving skills. But when Itard's attempt to teach this wild boy was not fully realised, an era of pessimism concerning the mentally retarded inevitably followed. However, in early 19th century itself Edward Seguin, one of the students of Itard, followed his lead in the prospect of training the mentally retarded. Seguin, in fact, devoted his entire life to develop procedures for working with the mentally retarded within an educational framework. Marie Montessori elaborated on the work of Itard and Seguin in the late 19th century by developing a programme of activities requiring utilisation of all senses.

Since the days of Itard and Seguin, almost every country has been actively involved in its attempt to cope with the problem of the mentally retarded including their education, training and rehabilitation in the community. The concern for the retarded has now become a phenomenon in all civilised nations, and with the industrialisation of the society the necessity of educating and training the retarded has increased manifold.

Education of the retarded must be understood in its broadest possible context. Education does not limit itself to only academic or mere textbook learning; rather it is more concerned with the all-round development of an individual. The problems of the retarded are varied. Not only have they limited intellectual and learning capacity which makes it difficult for them to handle the symbols in relation to reading, writing and arithmetic, but they are also incapable of having mature social and emotional relationships with peer group or others. The retarded has poor self-concept and lacks self-confidence in solving problems or getting along with others.

\*This paper is based on the lead paper 'Education of the Retarded' presented on April 22, 1981 by the author under the theme 'Education for the Disabled' at the 3rd All India Conference on Educational Research held at NCERT, New Delhi.





## PRINCIPLE OF NORMALISATION

An optimistic developmental model of mental retardation holds that the retarded is capable of growth, development and learning. The aim of giving education to him would be to help him to develop as a person so that he can manage his daily personal affairs and regular work and can get a job according to his potentialities, though his psychological abilities dealing with analysis, synthesis, reasoning, recognition, language communication, or numerical treatment may never reach the desired level. The aim of education should be considered in relation to the characteristics of the individual concerned. Even the most severely or profoundly retarded is assumed to have some capacity for developing higher levels of skill progressively. This optimistic view suggests that education and training must be provided to the retarded to promote teaching and development.

The principle of normalisation, an outstanding strategy has presently been recognised by all as one of the aims of education. While referring to the principle of normalisation, (Grunewald 1969) states that, "The term implies... a striving in various ways towards what is normal... normalisation does not imply any denial of the retardate's handicap. It involves rather exploiting his other mental and physical capacities so that his handicap becomes less pronounced...". Normalisation entails "making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of the main stream of society" (Nirje, 1969, p. 181). "Normalization (thus) is a process that employs as culturally normal means as possible to bring about as normal functioning by the retarded person as possible" (Neisworth and Smith, 1978, p. 87). The normalisation principles basically involve the principle of humanisation. It refers to the services, situations and attitudes which will bring about humane care of the retarded (Dybwad, 1973). It thus implies that the society provides a place for the mentally retarded in the community which is not contingent upon their being a normal (Gelman and Vitello, 1974). Of necessity, normalisation, therefore, demands availability of services with equal access for the retarded citizens so that they can have as normal circumstances and as least restrictive environments as possible.

## INTEGRATED EDUCATION

The concept of integrated education is an off-shoot directly emerging from the principle of normalisation. Historically, facilities for the mentally retarded were always considered separately from the regular school patterns. However, the recent trend seems to be in the opposite direction.

All types of provisions for services to the handicapped have passed through certain stages of development. Grunewald (1980) has identified such stages of which the first is the *diagnostic stage* where diagnoses are made





and plans are formulated to meet particular needs. The second stage is that of *specialisation* where particular needs are met by special solutions specific for those needs. The third is called the stage of *differentiation* in which stage it is realised that a particular service cannot be standardised for all recipients. The relevant factors in this respect could be different age groups, degree of retardation, and the like. The final stage is a composite one characterised first by *decentralisation* of services, then provision for integration of services to the retarded with those similar services available to the non-handicapped in the community.

The integrated education asks for special classes or schools within the grounds or in the premises of the regular schools with the idea that special education be integrated into general education as fully as possible. From the parent's point of view, integrated schooling appears to be less stigmatising. This will also extend an opportunity for the non-retarded children to have some interaction with the handicapped children. Ordinarily, prejudice, less compromising attitude, bias and ignorance prevail in most situations discouraging any close relationship between the two. However, under the integrated education scheme, the children as well as teachers would become exposed to the retarded which would help them to develop an understanding and tolerance for them.

Till recently education for retarded children in most countries did not form a recognised component of the national or any state plan of the education ministry. However, situation is changing fast and more and more countries are favouring an educational scheme which recognises that exceptional children need to be integrated with the so-called normal children in schools in such activities as games, physical education, school assembly, recreation, and hobby activities. They, however, need to be taken out of the regular class for remedial treatment where there is less class pressure and where their individual needs can be catered better. In Indonesia, in some rural areas the education of the handicapped children (which include the blind, the deaf and the retarded) has been integrated with regular schools. Here the special need of the handicapped children is met in part by visiting (specially trained) teachers who at regular intervals do the supervisory work to be followed by the regular teacher. The regular teacher thus needs to follow the progress of the child jointly with the special education teacher by reinforcing the remedial treatment in the class. Adequate use of programmed instructions and instructional games are imperative in this respect.

The Government of India has also recommended integration of schools which involves taking in mentally handicapped children in the schools for normal children, where they would take part in all activities and in classes in which they are at par with the other children. Special 'resource' teachers and special 'resource' classrooms have been recommended for the handicapped where they can be separately taught in class room subjects in which



they cannot participate equally with other normal children. The government has agreed to bear the expenditure involved here.

One of the major objectives of providing a normalised setting for the mentally retarded is that they must be in the least restrictive environment possible. In the US the concept of integration has been embodied in federal legislation in 1975 which is deemed to be implemented by PL. 94-142—Education for All Handicapped Children Act. The basic intention of this law is to prevent an individual from being stigmatised through classification and labelling. The public schools (government schools) have been entrusted with education and training to provide appropriate, individually designed, instructional programmes for all children, including the moderately retarded, to the maximum extent possible. More and more emphasis is now being given on the provision of instructional programmes for mildly retarded school-age children. This has replaced the earlier emphasis on provision of special education programmes for the severely and profoundly retarded.

The issue of integration, however, has its usual difficulties as well. For instance, it has often been pointed out that the attitudes of the so-called normal children towards their retarded peers might not be congenial, which might lead to rejection or even bullying. Prof. Miki (1980) has also expressed his doubts about the success of the integration programme in the field of education for the mentally retarded. According to him the characteristics of the aims and contents for the education of the mentally retarded has been slighted. He argues that the curriculum for the mentally retarded must be such as will be conducive to the saving of the limited mental energy of the retarded and the main emphasis would be on teaching minimum essential contents and training an individual according to his abilities which would help him in developing as a person and to get a job in the future. In a recent empirical study, Nalwa and Sen (1979), in fact, found that instead of mainstreaming the retarded, the special schools in a non-institutionalised setting were most beneficial for the retarded. In any case, the integration of retarded children into regular schools is highly unlikely to be complete so as to include all the severely and profoundly retarded.

#### *Nature of Education and Training*

The usual curriculum provided for the mildly and moderately retarded would not suit those youngsters with profound or severe retardation who most often need assistance in such basic skills as sitting up, chewing, swallowing, or going to the toilet. These developmental areas are the concern of the special educators who are to decide on the type of the curriculum needed, how such a curriculum could best be delivered, and what would be the facilitating environment most congenial to the development of the training programme for the teachers entrusted with the care of the children.

However, among the retarded population, only 5 per cent is assumed to be beyond any hope who need custodial care. Nevertheless, India being the



second most populous country in the world, its proportionate share of the severely and profoundly retarded becomes increasingly alarming. The nature of the care and training required for different categories of the retarded is not the same. The problem is deep rooted. Even the concept of retardation is not clear to many. The legal provision for the protection of the retarded is far from satisfactory. The attitude of the public towards the retarded is lamentably unfavourable. The literacy rate is very low in India. Around 80 per cent of the population in India are rural habitants. Many families do not even recognise the presence of a retarded child, unless the problem is severe, and when they look for some help from outside agencies. The number of such service agencies is also not large. The existing services cater for less than one per cent of the total number of the retardates.

Early identification and intervention would benefit the mildly retarded. Special education and training may be given to this group following the principle of normalisation as far as practicable. The impact of stimulus deprivation on the non-development of the intellectual and social competence has been widely documented (Sen, 1976). There is enough evidence that the type of stimuli to which a youngster is exposed during the first six years of life and the extent to which a youngster has opportunities to interact with a changing environment are directly related to the intellectual development of the child in the form of development of complex network of information. If the child is exposed to an environment comprised of a variety of stimulation, it encourages verbalisation, provides chances for exploration and gives ample opportunities for manipulating objects. Again, if the experience is rewarding, the child is expected to develop relatively a rich repertoire of information in contrast to a child who has been denied all such stimulations.

The self image of the retarded also needs to be developed. It may be possible to encourage them in expressing their ideas through painting, drawing, clay modelling, sculpture, etc. The Creative Growth Centre in California is doing a good job in this direction. 'Creative growth' is a community based programme for adults with mental, physical and emotional handicaps in Oakland, California. It provides a supportive, non-competitive art studio environment, counselling, communications and independent living skills, and also an art gallery to display the work of the handicapped participants. A dedicated husband and wife team, Dr. Elias Katz, a clinical psychologist, and his wife Mrs. Florence-Ludens Katz, an art director, started the Centre in 1973 with a grant from the office of Human Development of the U.S., Department of Health, Education and Welfare. It is a unique programme dedicated to the idea that all individuals, no matter how severely handicapped (mentally, physically or emotionally) can gain employment, enjoyment and fulfilment through painting, sculpture, print making, and can also produce works of high artistic merit. It cherishes to the conviction that all people including those with physical, mental, and emotional



handicaps, have the capacity to grow and develop as happier, more productive human beings through creative art experiences. The programme is geared to individual needs and many exceptions are made so that the handicapped can grow at their own pace, in their own direction. The individuals gain self-esteem while improving communication and social skills, part of the overall development of one's potential for independent living. Counselling and independent living skills are also integrated into the programme of the 'creative growth'.

In India, three artists from Jyothisangh, Ahmedabad, had won in 1979 international distinction for their works of art which were selected for exhibition at the prestigious 17th International Exhibition of Art by the Mentally Handicapped held in London.

The moderately retarded need special educational programmes which should aim at development in major learning areas. In addition to basic education in 3 R's, training in self-care skill needs to be given. This should include major developing areas like motor integration, perceptual and motor skills, language and communication, and conceptual skills. Special curricula may be developed and standardised for this purpose benefiting from the research findings by psychologists and educationists. One of the major impediments in the retardate's learning has been diagnosed as his attentional deficit which needs to be promoted/aided by making conspicuous some of the features of the learning situation. As a finding of some relevance, Nagpal (1980) obtained facilitatory effects by introducing a 'punishment procedure' in the discrimination process of the retardates. Herein, the retarded subjects were required to surrender back their much coveted rewards (earned on correct trials) as and when they committed errors and this disincentive scheme made them concentrate more. The retardates may be given special training leading to practical help in their day-to-day life, such as dressing, independent movement, handling of money, maintaining personal hygiene, learning to communicate about their needs, self-help, etc.

Creation of more service centres and day care centres leading to development and training of the moderately and severely retarded is needed. Day care centre has been looked upon as a model form of care in most of the countries as has been noted in the WHO workshop of the South East Asia Region held in New Delhi on September 12-16, 1978 for the 'development and strengthening of mental retardation programmes'. It is less complicated to institute and less costly to maintain the desired level of care and at the same time, it preserves family ties. The consensus of the workshop was to emphasise day care as the more generally applicable setting for retarded children of school going age. Grunewald (1980) also commented that "an influence for favourable development is to be found partly in the small number of interpersonal relations forced upon the retardates thus making them potentially stimulating rather than frustrating, and partly in the homelike atmosphere and equipment of the room and of the unit to which



the room is connected". (Grunewald, 1980, p. 66).

Creation of small, parent-initiated facility in diversified forms for the retarded children, outside the mainstreams of professional educators and administrators, has received impetus in recent years. The advantage of adopting the principle of 'small environment' for the severely retarded where the number of persons for interaction is limited to a group of 5 to 8, or even less, has been outlined by Grunewald (1980). He has emphasised a caring atmosphere and day facilities that preserve the ties with families.

The significance of an early education programme and the nature of pre-schooling programming has been detailed by Neisworth and Smith (1978). In the Indian context Malhotra (1979) has also suggested some development of educational programmes including home-stimulation programme for the retarded. In a bid to deal with the practical aspects of the mentally retarded, FWMR (India) also recently gave a call for essays for competition leading to practical programmes concerning curriculum/training schedules for the mentally handicapped. A number of such essays (Ahear, 1979; Radhakrishnan, 1979; Shamim, 1979) have shown sufficient merit which deserve follow-up.

The profoundly retarded who need custodial care constitute only a small portion of the retarded. More institutions may be started in all the States to look after such cases. Adequate trained personnel may be employed in such institutes. The families who cannot bear the life-long burden of the profoundly retarded children, emotionally and/or financially, need to be helped by the State. This situation may occur to any type of family background, irrespective of race or creed. If the families can afford, they should pay for the care of their wards in the institutions, according to their income, in case they are not willing to keep such cases at home along with them. Conversely, if some families want to keep such children at home, but cannot afford it, they should be given help from the State.

### *Vocational Training of the Retarded*

Academic achievements are relatively unimportant in comparison to social adaptation and vocational training of the mentally retarded. Vocational training is the only means of making the mentally retarded economically and socially self-dependent, at least partially. A civilised society is keen to see that even its most humble member, with severe shortcomings, be it physical or mental, finds a place in it, without unduly living a parasitic life. In this context scientific enquiry is of utmost importance to tap the abilities and limitations of these less fortunate inhabitants. So far as the mentally retarded is concerned, there is also a growing consciousness in recent years that at least some of them can achieve a reasonable degree of adjustment to work and social life. This conviction is receiving impetus from research findings all over the world. The last few decades have witnessed various efforts made by investigators in different countries for



evaluating and predicting the potential of the retardate for vocational rehabilitation.

Vocational schools for the mentally retarded adults are not too many in India; as a result, many of the retarded do not find suitable jobs even after education and training in special schools. The sheltered workshop is the ideal for employment of the trained mentally retarded. A sheltered workshop serves as a transitory place for the mild and moderately retarded to receive training in various trades and crafts, to develop more skills, and provide opportunities for jobs in the open market. The training is provided in a sheltered atmosphere. Structured work problems which vary in complexity can be created to develop work capacity. Sudden transition to work environment is not easy; on-the-job training and sheltered workshops are necessary to protect the retarded from the stresses of competitive work situations. For the mentally handicapped adults, sheltered workshops, farms and employment by industries are needed. For the severely retardates and many moderately retarded, who are not capable of receiving open employment, sheltered workshop is the only answer for employing them permanently. After receiving training they work on various sub-contract works received from various agencies.

The process of job identification is not so easy when planning for the employment of the mentally retarded worker. Jacobs, *et al.* (1979) have given a source of general information on appropriate jobs, which is designed to help the counsellor locate these jobs and employers within the community. The 158 job profiles are arranged in 6 related groups: (1) merchandising occupations, (2) office occupations, (3) service occupations, (4) agriculture/fishing/forestry, (5) skilled trades, and (6) processing and manufacturing occupations.

Training can be given both for vocational and pre-vocational phases of a training programme. Different types of training programmes may be conducted in a variety of combinations and settings. Training could be in basic skills which refers to the preparation of the trainee in the fundamental and academic skills such as reading, writing, and typing that are applicable to almost all jobs. The second is training in core skills providing the trainee with experience of more complex activities, common to a particular group or general groups of jobs. The third type relates to the preparation in specific skills required by the trainee in which he is to be placed. Finally, the work adjustment training which pervades all aspects of training and is concerned with motivation, work attitudes, work habits and productivity. In a recent work Sen (1981) has reported the findings of an empirical study dealing with the appropriate manipulation of certain variables which would have a beneficial effect in bringing into the universal transfer phenomenon among the retarded, including the moderately and even a few severely retarded.

Vocational training and education of the retarded should train them for an independent living as far as possible. Work may be given to them with





financial recompense. The staffing pattern and the training of the staff employed should be given due attention.

The 'goodwill' industries in some western and eastern countries mainly employ the retarded. These industries were first organised in Boston in serving the disabled, the vocationally handicapped and the vocationally disadvantaged, by providing vocational rehabilitation services and training opportunities for personal growth and community placement. There are now 160 non-profit autonomous members of 'goodwill' industries of America, Inc. which constitute the nation's largest private rehabilitation programmes serving 60 per cent of the American vocationally handicapped persons. William C. Wieggers, the executive director of the industries of the Greater East Bay says: "No matter what abilities a person has lost, other abilities remain. The first big step in giving new hope to a handicapped person is to find what he can do best. . . it is a living faith, for by it we mean service, team work and a genuine belief in our individual responsibility towards our fellow men, convinced that the true object of all help is to make help unnecessary". 'Goodwill' trains persons with mental, physical or social disability, for jobs that they can do such as warehousemen, food services, sewing, drycleaning and laundry, upholstery, woodwork, small wares repair, and bicycle repair. The training in a specific field is provided in accordance with the trainee's own efficiency and employment potential. The training is also geared to specific demand for unskilled or semi-skilled, as available in the communities' placement market.

Today, 'goodwill' is international in scope with the active support of people of many faiths. There are many 'goodwills' throughout the US, Canada and other nations. Each local unit operates independently relying on its own community to formulate and execute its programme. Their venture has well paid off, as the commodities they sell are procured from different families, who want to dispose of their old belongings, used or unused, free of cost. In exchange the donors get substantial benefit in terms of tax exemption due to their charitable gift. The scheme is working well, the consumer gets the product at a very low price in contrast to market price and the other parties involved are equally benefited from such endeavours. Though it is not sure whether such a scheme would also work with such efficiency in India, the project is worth trying.

### *Residential Facilities for the Retarded*

In developed countries, there are ample resources to have elaborate schemes for the welfare of the retarded. The system suits the specific culture and demand as the families have neither time nor will to continue with the retarded children. State's help is readily available, and whenever the families can afford, they pay for their wards after sending them to retarded home and institutes. The 'Clausen House' in California, provides a residential house for the retarded adults and gives them practical training



as well as pre-vocational training. The House gives a number of residential facilities for the retarded and is operated by a non-sectarian, non-profit corporation under the sponsorship of the Episcopal Diocese of California. It provides active programming throughout the week in a residential setting which includes elaborate instructions in the basic skills of independent adult living and additional training in living skills. Recreational activities are also included in the programme to enhance the residents' abilities to plan and structure leisure time. The special project 'Goal' (greater opportunities for adult living) is an apartment facility which provides a semi-independent living situation for those Clausen House residents who are ready for an intensive, individualised programme in independent living.

The retardates should have a chance, if they so desire, of independent living and working, away from their own family. However, the issue of their residential facilities needs to be worked out individually for each society and culture. In the Indian context, it seems that whenever possible the family may be encouraged to look after their own retarded off-springs (irrespective of degree of retardation) for which the family may be provided financial assistance, particularly when the retarded is not gainfully employed in a sheltered workshop or in an open industry. The failure of the institutionalisation programme and state hospitals in the west should point out the correct perspective in the Indian setting. The family bond is strong enough in India, the child should be absorbed in the family as far as practicable. The concept of mother-teacher needs to be given proper consideration. If the mother devotes time for the retarded child in a natural environment, all encouragements and material incentives should be provided to the family. The state may give financial assistance to the family. Weekly classes for the parents of the retarded may be organised in different localities which would enable them to be acquainted with the probable solutions for various problems faced by them. Also, they would be able to interchange their ideas and views regarding the problems of their off-springs with the fellow parents. Residential facilities may be provided for those retarded whose home environment is not congenial or whose condition is so bad as to demand care which the family cannot afford.

Proper legal provisions need to be made for the protection of the retarded against exploitation and their innocent involvement in law related problems (Sen 1978). Coordination of professionals concerned with the problem of the retarded may be effected in the form of periodic organised meetings at different locations. Need for public awareness about the problem of retardation and the development of the correct attitude towards the retarded is another prerequisite.

#### *Training of the Personnel*

Any programme in the service of the retarded calls for a coordinated effort by all agencies in an attempt to ameliorate the conditions of the





handicapped and to rehabilitate him into the community. Needless to mention, the government both at centre and state levels, local authorities, voluntary agencies and public at large should work in this direction.

The very nature of the problem of retardation involves persons of different professions with diversified background in training and education. Adequate training and education of all personnel involved is of primary importance. Medical practitioners, specialists, psychologists, teachers, social workers, technicians, all should receive a good background knowledge in the subject of retardation.

The task of training the personnel is not simple. However, the most valuable resource for the retarded is his teacher and staff. It is, therefore, of utmost importance that the staff should be properly trained. Therefore, special emphasis should be laid on the training of teachers of the handicapped about modern techniques of education, training and management. Recognising the need for trained teachers for the handicapped, the first training programme for teachers was started in 1955 in Bombay at the School for Children in Need of Special Care. Since then three more institutions have started teacher-training programmes.

Training programme would also involve training of personnel for residential institutions and day care centres. Similarly trained personnel is also needed for imparting pre-vocational and vocational teaching to the retarded. Training of the parents is another important concept. The emphasis on parental involvement in the education of their handicapped has received increasing recognition over the last decade. The rationale for parental involvement, and in consequence their training, has been expounded by Prof. Peter Mittler in a lecture in 1979 organised by the FWMR during his visit in Delhi, (Mittler, 1980). It is of utmost importance that parents, particularly mothers, should receive adequate guidance for promoting physical and mental development of the retarded offspring. They also need counselling for their own psychological adjustment in accepting that their child is handicapped. Guidance to parents and their involvement, particularly in the pre-school training of the child, is of utmost significance. In fact, the whole family of the retarded is in need of help, both economical and psychological.

#### CONCLUDING REMARKS

Though the exact number of the retarded in India is not definitely known, it has been estimated that there might be about 24 million retarded (Sen, 1981). Prabhu (1979) has indicated that taking the average Indian family size 5-6, one out of every 8 to 10 families is directly facing the problem of mental retardation, though a majority of them would be only mildly or moderately retarded. In Delhi itself about 2,000 cases are diagnosed as retarded every year; the existing facilities absorb about 100 of them. To



date, there are about 150 known institutions in the whole country providing 8,000 beds for a population of 24 million retarded. The institutions provide clinical, medical, educational, vocational, pre-vocational, teacher-training, research, psychotherapy and other services. Of these, educational and vocational programmes are more common and psychotherapy is the least. The services which are now available are primarily in major metropolises, and many states and cities do not have any facilities at all. Most of the institutions are either run exclusively privately or privately with some aid from the state/central government.

The facilities available for habilitation of the retarded are far from satisfactory. Adult retardates have received the least attention anywhere in India and facilities for them are relatively few throughout the country. Neither the private organisations nor the state authorities have dealt sufficiently with the problem of the mentally retarded adults. In recent years, however, attempts are being made in several parts of the country to devote some attention to them.

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## Rehabilitation of the Leprosy Disabled: Policy and Organisation

J.M. Mehta

**L**EPROSY IS a chronic bacterial infection affecting mainly the skin and nerves. Yet from the medical and social stand points it is a highly misunderstood disease. There are two main varieties, lepromatous and non-lepromatous. In India 20 per cent of the sufferers belong to the lepromatous group. It is this group which spreads the infection *when left untreated or inadequately treated*. The remaining 80 per cent may be considered to be non-infectious but can suffer from severe physical deformities due to affection of peripheral nerves which bring about loss of sensation of the hands and feet and paralysis of the small muscles of the hands and feet. The paralysis of the hand brings about the typical 'claw hand' deformity. Loss of sensation removes the protective phenomenon of pain so that the patient does not take care of injuries and burns to his hands and feet. Ulceration then takes place and secondary pyogenic infection brings about rapid destruction of the fingers and toes. Deformities also occur on the face especially in the lepromatous variety and all these deformities put together produce the hideous picture of leprosy as fixed in the lay public mind leading to all the misunderstanding and stigma about this disease.

Proper medical treatment along with the care of hands, feet and eyes would result in minimal deformity. But this is the ideal situation and we have upon our hands thousands of deformed leprosy patients who have been out-casted from society and for whom something has to be done urgently. Rehabilitation, therefore, in these cases must be carried out.

In this article we shall restrict ourselves to socio-economic rehabilitation but it must be remembered that medical and physical rehabilitation by physiotherapy, reconstructive and plastic surgery, protective footwear for plantar ulcers and other such measures form a major aspect of any rehabilitation programme.

It is our initial duty to see that the leprosy patient does not undergo a process of 'dehabilitation' which can be prevented by early diagnosis and proper treatment. Notwithstanding this ideal situation the word 'leprosy' strikes terror not only in the mind of the patient but also in the public, and this fear can be treated only through aggressive health education.



The stigma brings about an unsympathetic public and even official attitude. Though the present policy of government is to assist the leprosy patient, this does not work in practice due to lack of personnel and lack of motivation on the part of the latter.

Being a communicable disease, the Government of India took up the National Leprosy Control Programme (NLCP) under which surveys are carried out for the early detection of cases which are then put on treatment, but treatment does not consist merely in doling out tablets. Plantar ulcers, dry and easy traumatisable skin, leprosy neuritis, lepra reaction and several socio-economic problems of the patient should also be taken into consideration if the programme is going to be popular and retain patients under treatment for several years which is necessary. It took the Government of India more than 25 years to decide that rehabilitation should also form an important aspect of the NLCP. To quote an example of the lack of understanding in official circles, I would like to mention about the case of one of our very esteemed and highly educated patients who was very badly deformed but worked most efficiently and with great zeal and enthusiasm in our institution till the day he died. Such a person, when recommended for the national award for the most efficient physically handicapped employee, was not given the award on the premise that leprosy did not figure in the categories! Orthopaedically handicapped are in the category and the motor and sensory loss which takes place of the hands and feet in leprosy is a straightforward orthopaedic handicap; and yet this patient was not considered in that category. I would say not because he was suffering from leprosy but because of the stigma about the disease. If I had mentioned that his deformities were due to some disease other than leprosy I am sure there would have been no difficulty! So powerful is this fear and phobia of leprosy in official minds as well. Perseverance at last brought about success and the said gentleman—a life that had benefited so many others—was given the award in 1979, to the best of our knowledge the first of its kind in the country, that is, for the first time to an ex-leprosy patient.

Another illustration of the leprosy stigma: A lady was very keen to work in the office of a leprosy hospital. She visited the hospital and wanted to offer her services in an honorary capacity for which the administration was thankful. After she went for one day, the very next day she approached the management that it would not be possible for her to work because her neighbours in the housing society had objected on the ground that by working in a leprosy institution she would bring the infection into the housing complex. This was their attitude in spite of explaining to them that she was only going to work in the office block which is separate and at a distance from the hospital wards. Some of her neighbours even threatened that they would not allow their children to play with her children. A neighbour highly qualified in the subject of sociology told her that it was dangerous to work in a leprosy institution and that she would be spreading infection all round her and wherever she



went.

A similar prejudice operates with doctors and nurses and it is so difficult to get medical personnel to work in leprosy institutions.

#### REHABILITATION PROBLEMS

Rehabilitation in leprosy is easy as it is found that, with training, a moderately deformed patient can perform several jobs efficiently including light industrial work on normal general purpose factory machines. But the stigma comes in the way as nobody wants to do anything with a cured leprosy patient resulting in the large number of beggars and anti-social elements associated with them who move around every city and town in our country.

Another encouraging feature is that once the cured patient starts earning well he is assimilated back into the community more readily.

Another factor that interferes is the medical certification of fitness in the case of lepromatous leprosy patients. Such patients show the presence of leprosy bacilli in their skin smears for several years though with adequate chemotherapy they become almost non-infectious within 9-12 months. But the government directive is that he cannot be made fit till all his skin smears are negative on repeated examination. As it is impossible to achieve this, the man loses his job adding to the problem further. This requires rectification and a strong plea for bringing it about has been recommended to the government by the National Leprosy Advisory Committee. The present policy appears to be that we do not want a lepromatous patient to remain on his job as he may infect us—which also is not true as mentioned above—but we do not mind if he is removed from service and is away from us but now, because of irregular treatment, becomes infectious and because of economic starvation moves about everywhere infecting our brothers and sisters in the open community. The 'leper' was out of sight and hence out of mind. The problem of leprosy had been swept under the carpet and all was well. What an unfortunate policy we have been following all along!

If government gives the lead then the public sector and the private sector industries will also take a proper view of leprosy and the removal from service of hundreds of leprosy patients would be prevented.

#### ADMINISTRATORS' LEAD

Thus, a radical change in our thinking and attitude and especially for those who would become administrators in government, taking all sorts of courses in public administration, is imminently needed. Every administrator should know about leprosy and should look at it in the correct perspective. Any amount of legislation is not going to rectify the situation. But if public officers give a proper demonstration, by showing the correct way, it will help greatly in changing the present public attitude to leprosy. It must be



remembered that we are dealing with a human problem and, therefore, though we may not be absolutely scientific in our approach, compassion is of importance and would form a major factor in the success of such welfare schemes. Otherwise, most of the projects which look very good on the face of it would remain merely as schemes on paper. Presently, this is indeed true of several schemes for the handicapped, especially when concerning the leprosy handicapped.

A simple thing like travel for the leprosy patients is so difficult and if we are to help them we shall have to give up our lukewarm attitude and lack of understanding before something really good and concrete is done for them.

The leprosy beggar problem is generally connected with the main beggar problem in the country, and those who have become professional beggars cannot be given much assistance. But we could certainly help out by preventing the leprosy patient from becoming a beggar as it happens so often because of the unsympathetic and unkind attitude towards those suffering from this disease.

I feel that the integrated approach for bringing about substantial rehabilitation and for breaking the stigma should be implemented. In such a programme cured leprosy patients with or without deformity should be given vocational training with the ultimate aim of rehabilitation along with the orthopaedically handicapped but not due to leprosy, other handicapped persons like those with loss of vision and finally, the group should also include the socio-economically disadvantaged but able-bodied individuals. Such a programme is in its experimental stages in our institution and we hope to produce some interesting results in the next few years.

It has been our experience that institutions, governmental or non-governmental, have refused to accept cured leprosy patients for the purpose of vocational guidance and training. This is the tragedy of leprosy, and, therefore, the integrated approach that I have mentioned in the preceding paragraph would best be carried out by a leprosy institution initially and later it could be adopted primarily by non-leprosy organisations.

#### SHELTERED WORKSHOPS

This being the International Year of Disabled Persons we have a tendency to look at the European or American model but conditions in our country are different, there being a very large rural component and a considerable load of deformed leprosy patients. These two factors do not operate in the European and American situation and we would, therefore, have to devise our own methods to overcome the problem.

For certain patients—and this is quite a large number—who have lost all family contacts and at the same time may be having a high degree of deformity we would have to provide sheltered workshops, once again in an





integrated form and under the aegis of a leprosy institution.

At present it is well-nigh impossible to get leprosy patients employed in open industry which means that after their training they may have to be re-settled in self-employment. Such schemes of self-employment have indeed proved successful but after a lot of spade work because at every step the leprosy stigma interferes. Social welfare facilities like bank loans for the poor section of society are denied to leprosy patients on the premise, 'how will a leprosy patient earn in order to repay the loan?' This we have broken through and many patients have received bank loans and have repaid them with a much less defaulter rate than among non-leprosy cases. Even then all these facilities are marginal and much more requires to be done for the leprosy handicapped.

Figures, when they are very large as in India, become irrelevant. There are  $3\frac{1}{2}$  to 5 million leprosy patients, millions of other handicapped, making one feel that the programme should be very well worked out. In doing this several committees go on deliberating for years while the number of the handicapped goes on increasing at the same time. What is required is: Let us carry out the work with dedication and help at least some of our people without attaching too much importance to social science techniques and to mathematical cost-benefit ratio and such outwardly apparent rationalisation when we all know that it is not possible to measure human values and happiness in terms of money. It is here that the public administrator would play a crucial role encouraging schemes of human value and not making too much of technicalities, especially with regard to such a challenging subject as leprosy; otherwise he would be only showing bureaucratic cruelty to the leprosy patient.

I am confident that the cost-benefit ratio is very favourable and it is my plea to those who are studying public administration, with a view to becoming the nation's planners and administrators; that there should be no hesitation in sanctioning and in proper implementing of schemes of human welfare, and our motto should be: 'To get on with the work.'

#### PREJUDICE ALL OVER

Even in collection of funds by an institution having the provision of maximum tax exemption in the hands of the donor there is a bias against leprosy. 'Oh! what will the leprosy afflicted do with funds? They are already outcasted and in the last stages of existence, what benefit will accrue to them, how can we buy and handle products manufactured by them? By being close to us they will only propagate and spread the disease more. They should be pushed into the interior parts of the country. Why not, therefore, give for some other cause which will also be more dramatic and publicised.' This has been our experience, and to quote an example, tailors working in one of the large government hospitals objected to the stitching of bedsheets





and clothes made of cloth manufactured by our powerloom section saying that they were getting itching all over the body because the cloth was manufactured by cured leprosy patients! Under some pretext or the other material fabricated in leprosy institutions is quite often rejected.

Family planning should be vigorously pursued though it may be felt that we are treading on human rights and constitutional safeguards but then we must think about the children who would be suffering from the disease—though by suitable treatment and better living conditions, both of which are not available, this can be prevented—and consequently undergo much suffering. Don't we care for them? Does not a child have a right to a healthy life? The planners and policy makers must keep this aspect foremost in their minds.

Rehabilitation cannot be carried out haphazardly. It should be accompanied by health measures and health education, undertaken by experienced persons in the field. But then there are very few trained and experienced individuals in the field of leprosy. I feel that much stress should be given to health education in leprosy; I mean for the public and especially for those in positions of power—politicians and officials. With a little scientific education about the disease one may be able to overcome age-old prejudices. But we have seen that this does not take place, and the main factor which would overcome the stigma could be the virtue of compassion. In conclusion the following points may be recapitulated:

1. Leprosy is a mildly contagious disease.
2. It is not hereditary.
3. It is curable.
4. Infectious cases become rapidly almost non-infectious when kept on adequate modern chemotherapy.
5. The degree of deformity is not a measure of infectivity. As a matter of fact, many of the highly deformed patients are of the non-lepromatous variety and completely non-infectious.
6. Rehabilitation is possible through vocational training centres.
7. Self-employment is an important means of resettlement.
8. Sheltered workshops would be required for a certain percentage of cases.
9. Leprosy stigma is the one single interfering factor in implementation of rehabilitation schemes.
10. To break the stigma an integrated approach is feasible and seems useful.
11. Government departments and government officials must give the lead in leprosy programmes showing thereby conquest over stigma. This can be achieved not only through scientific understanding but in a great measure by the application of compassion and dedication.



If our message reaches the readers of this article we shall feel that we have achieved much in this neglected and highly misunderstood disease.

Are there any chances that by taking the above measures we would be increasing the spread of leprosy? According to epidemiological studies a prevalence rate of one patient per thousand population constitutes a health hazard. In India the general prevalence is 5 per thousand, and we are all exposed to a certain measure of danger which is not increased at all by the measures given above. As a matter of fact, with the disease coming more into the open and with greater stress being paid to it and with greater number of patients undergoing treatment the danger of spread should diminish. Therefore, the answer to our above questions is an emphatic 'NO'.

There are several government schemes for the rehabilitation of handicapped persons. There are also directives that handicapped persons should be given job preference and even legislation is mooted to reserve a certain number of jobs for them. Leprosy is supposed to come under the orthopaedically handicapped group but this does not take place in practice. Any amount of social welfare legislation will not solve the problem. Therefore, the job selection and other panels constituted by government should have on them a leprosy worker interested in the welfare of leprosy patients and having some experience of rehabilitation work and above all he must not himself suffer from the stigmatised attitude about the disease which is universally prevalent.



## Emerging Concept of Welfare of the Physically Handicapped

**S.R. Mohsini**

**T**HE PEOPLE with a physical defect of one kind or the other were described for centuries as cripples. It is only recently that they are identified by a new term, *i.e.*, the physically handicapped or the disabled. The change in terminology is quite significant as it indicates an emerging concept of their welfare.

The physically handicapped were considered for centuries as incapable of leading independent lives. They were believed to remain dependent on their relations, neighbours or fellow human beings for food, clothing, shelter and other amenities. Their protection and care was regarded as an act of religious merit, as a means of spiritual salvation and as a pious deed inspired by human sympathy and philanthropic zeal. They were, in fact, taken as an object of pity and charity and were deprived of human dignity and self-respect. This approach not only forced the unfortunate ones to beg in the street but also made them an easy victim of exploitation by those who took them under their charge and collected money by arousing the pity and sympathy of the masses towards the afflicted ones.

The introduction of aid and assistance to people in distress on an individual basis paved the way for specialised services to different types of the physically handicapped. The advancement made in medical science, pedagogy, and social sciences helped the physicians, educationists and social workers to be optimistic about the possibility of curing physical disabilities and of educating and rehabilitating the disabled persons. All these developments revolutionised the concept of welfare for the physically handicapped. Now people increasingly believe that a handicapped person, if given proper treatment and right opportunities for rehabilitation, can lead a full, free and independent life and can become an economic asset to the country instead of a burden on himself, on his relations, on neighbours and on the general public and the state. It is with the growth of democratic ideals and institutions that welfare measures for the physically handicapped came to be considered as a human and fundamental right. The preventive services and programmes for treatment and rehabilitation of them are now seen as a part of the total programme of a democratic and welfare state for



providing equal opportunities to all its citizens.

Equal opportunities for the handicapped person mean that as an individual with human rights, he should be assured the facilities to attain equality of status and opportunity. Taking into account the disabilities of the handicapped, it is necessary that he/she may be provided with special facilities for protection, assistance, education, training and rehabilitation. It is believed that if given right opportunities the handicapped is capable of developing his residual capacities, powers and talents and of becoming economically and socially independent.

### EQUAL OPPORTUNITY

The concept of equal opportunity for the handicapped made it necessary to develop a new approach to the problems of their welfare. A document of the United Nations on rehabilitation\* elucidates the new approach to the problem of the handicapped and the new concept of their welfare:

The time has long passed when a handicapped child or a disabled adult should be regarded as a subject for commercial exploitation and trained for the occupation of a professional beggar, or even to be considered as a mere object for charity. Modern methods of medical and sociological science have opened up a new horizon of promise for such individuals. But if this promise is to be fulfilled and the handicapped person is to have his full chance of life, there must first be a new evaluation of physical disability, based on the following theses:

Firstly, that the handicapped person is an individual with full human rights, which he shares in common with the able bodied, and that he is entitled to receive from his country every possible measure of protection, assistance, and opportunity for rehabilitation.

Secondly, that by the very nature of his physical handicap, he is exposed to the danger or emotional and psychological disturbance, resulting from a deep sense of deprivation and frustration and that he, therefore, has a special claim on society for sympathy and constructive help.

Thirdly, that he is capable of developing his residual resources to an unexpected degree, if given the right opportunities of so doing, and of becoming in most instances an economic asset to the country instead of being a burden on himself, on his family, and on the state.

Fourthly, that handicapped persons have a responsibility to the community to contribute their services to the economic welfare of the nation in any way that becomes possible after rehabilitation and training.

\*Usha Bhatt, *The Physically Handicapped in India*, Popular Book Depot, Bombay, 1963, p. 19.



Fifthly, that the chief longing of the physically handicapped person is to achieve independence within a normal community, instead of spending the rest of his life in a segregated institution, or within an environment of disability.

Sixthly, that the rehabilitation of the physically handicapped can be successfully accomplished only by the combination of medical, educational, social and vocational services.

The first task which, therefore, confronts all international agencies is that of using all possible means to secure general acceptance throughout the world of this new conception of physical disability.

### NEED FOR SOCIAL AWARENESS

The objective of providing equal opportunity for the handicapped can be achieved only if the social philosophy underlying the new approach to their problem and the new concept of their welfare is accepted by the general public. It has to be given wide publicity. People at large have to be made aware of the possibility of rehabilitation of the disabled children and adults. In many countries of the world, having a handicapped child was and in many places still is a mark of disgrace.

The general public need to be convinced that disabled persons are handicapped as much by the attitude of the society as by their physical limitation. The tendency to isolate the person with physical defect need to be replaced by a realisation that a handicapped individual is first a person and only secondly a handicapped one. He must be dealt with as a whole person with physical, mental and emotional needs.

There is also the need of changing the attitudes of the handicapped themselves towards their physical disability. This objective can be achieved through effective provision of the recently developed rehabilitation programmes so that the disabled may simultaneously understand their limitation and realise their obligation to make their maximum contribution to society. Moreover, the physically handicapped, their relatives and the general public have to be informed about scientific investigations made in respect of physical defects which have proved that physical capacity or incapacity is a relative matter, no one is physically perfect and only a few are totally disabled. A person according to this discovery cannot be considered unfit for all work if he is not able to do a particular work. Physical disability is now considered to be related to a particular job or a particular task and it is, therefore, the function of the integrated science of rehabilitation to help and guide the person with some physical defect as to what kind of job and work he can select for himself, and train him for the same.

The acceptance of the social values and the recognition of the new factors about physical disability brought about by the developments in medical and social sciences led to the evolution of an integrated pattern of medical,



social, educational and vocational service in recent years which is indeed the most significant advance in reducing the problem of disability. These services are provided in hospitals, welfare institutions, schools and employment agencies. Due to the sporadic nature of their development most of the handicapped find it difficult to get the benefit of one or the other services which they need. It is now imperative to have comprehensive and integrated services so that each handicapped individual receives all such services necessary for bringing about his maximum rehabilitation.

The rehabilitation of the physically handicapped, therefore, requires the cooperation of many professional disciplines. A mere listing of all professions participating in the rehabilitation programmes, such as medical practitioners, social workers, educationists, specialists in vocational guidance, etc., indicates the nature of the programme of rehabilitation for the disabled. In the medical setting we find doctors, nurses, social workers, occupational and physical therapists, speech specialists and prosthetic technicians, etc. The number of specialists involved in the work indicates a number of phases in the process of rehabilitation. Medical care is only one of them. Preventive medicine is now accepted as another phase of medical programme. Physical rehabilitation is now well understood as the third phase of medicine. The integration of medical services with other aspects of rehabilitation—social, educational and vocational—has recently started to receive further consideration.

This venture in the field of welfare for the physically handicapped is based on the belief that it is their human right to secure equality of status and opportunity and to be assured of respect and dignity as human beings. The traditional patronising attitude of the society in providing some sort of assistance to them is against the modern spirit. It is now obligatory on the society to provide to the physically handicapped, all the services which they require for leading fuller, free and independent lives. The segregated existence of the handicapped individuals in special institutions, sheltered workshops and residential houses in isolation from the community is outmoded and inconsistent with the modern concept of equality of status and of opportunity. What is required is to make a conscious and sustained effort to bring about the social integration of the handicapped with the rest of the society.

#### INADEQUATE DATA ON THE HANDICAPPED

We have only sporadic provision in India for the integrated service for the education, training and rehabilitation of the handicapped. Those who avail these services become productive and participating citizens. But there are many who cannot get these services at all. What is needed is the extension of the existing services to rural and other backward areas in the country. Communities and areas which cannot individually support these integrated



services should be covered through mobile clinics and service units which may supplement the existing services in the rural areas or refer to the agencies available in the adjacent districts. But there is great dearth of reliable data to show the number of disabled people in the country and the nature and extent of their handicaps. The only data available is based on a series of sample surveys conducted by the Indian Council of Medical Research. They could not be expected to give a clear assessment of the situation. The required information has to be collected on a regional basis so that the integrated services might be extended to areas where they are most needed. The infrastructure at the national level has been evolved with the establishment of national institutes for different kind of handicaps and with the introduction of different schemes for the welfare of the physically handicapped. The extension of these services could be done easily if a mobile preventive unit is attached at each district organisation of the primary health services. Such units could not only assess the situation but also provide guidance for the prevention of physical disability and make periodical recommendations for the extension of the integrated services in the area.





# **Legislation for Rehabilitation Services for the Disabled in India**

**Mukkavilli Seetharam**

**L**EGISLATION FORMULATED to bridge the gulf between the existing laws and the current needs of the society may be called social legislation. The present paper gives a descriptive and analytical review of the existing legislation concerning disabled persons in India. In the process, some basic issues confronting the rehabilitation of the disabled are highlighted and a few suggestions made, considering their core needs and experience of other developed and developing countries in this field.

Several writers draw a parallel between the stage of civilisation in any country and refinement of its laws concerning different groups of people. For the disabled, among other things, factors such as the levels of social development; economic advancement; concept of social security and social welfare policies; availability of trained personnel, degree of mobilisation of disabled groups; availability of voluntary agencies; and the economic and social problems and priorities of the given country—all these considerably influence the enactment and implementation of the legal provisions in their favour.

## **DISABILITY AND HANDICAP**

A clear understanding of the concepts of disability and handicap is necessary in formulating legislative action for rehabilitation. Disability is defined as any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being. Handicap is a disadvantage for a given individual, resulting from an impairment, or a disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual (World Health Organisation, 1980: 207). Disabilities are of two broad categories: physical and mental. The physically disabled include the blind, the deaf, the dumb, and the orthopaedics. A disability becomes a handicap when it interferes with one's ability to do what is expected at a particular time. Rehabilitation is an integrated programme in which medical, psychological, educational, social,





vocational and economic services are geared together in a continuous process.

### *Major Approaches*

There is a growing tendency among the developed and developing countries to provide rehabilitation services for the physically and mentally disabled through legislative action. Broadly speaking there are two major types of legislation concerning the disabled. First, a number of legal measures concerning the general population have regulations relating to prevention of disability. A few of them relate to industrial accidents, consumer protection, traffic regulation and other safety codes. Provisions are made in cooperative law to enable disabled persons to join agricultural cooperatives. The second group of legislative acts becomes operative after a person becomes disabled and is exclusively for the disabled persons.

### *Constitutional Provisions*

In India, laws relating to the handicapped come under the VII schedule of the constitution's concurrent legislative list. Article 41 of the constitution directs the state, "to make effective provision for securing the right to work, the education and public assistance in case of unemployment, old age, sickness, disablement and other cases of undeserved want". Article 46 provides for promotion, with special care, of the educational and economic interests of the weaker sections and to extend them protection from injustice and all forms of exploitation.

### *Job Reservation: Union and State Measures*

There is an executive order issued by the Bureau of Public Enterprises for public sector undertakings and another by the Union Ministry of Home Affairs providing for a job reservation of one per cent each for the blind, the deaf and dumb and the orthopaedically handicapped in class III and class IV posts of the Central Government and in public sector undertakings. However this is not a statutory requirement and unfortunately there is a lack of proper machinery to monitor these reservations by the concerned employers. In India, there are 169 public enterprises in 1979-80, with a capital of Rs. 16,354 crores and giving employment to 1.76 million persons (Government of India, 1981: 38). Hence it is imperative to evolve suitable monitoring procedures to ensure that the provision for the reservation does go to the disabled.

At the State level, according to information available, 18 states have job reservation for the disabled. The exceptions are Assam, Bihar, Kerala, Tamil Nadu and some Union Territories. In the states, the percentage of reservation varies from one to four, the lowest being in Orissa and the highest in Gujarat. The states which give unemployment allowance to the disabled are: Andhra Pradesh, Bihar, Gujarat, Karnataka, Madhya Pradesh,



Tripura, Haryana and Punjab. Five Union Territories—Chandigarh, Delhi, Goa, Mizoram and Pondicherry—propose to introduce unemployment allowance for the disabled persons in the future (Indian Institute of Public Administration, 1981: 5).

There is no apparent rationale behind fixing a uniform one per cent reservation in posts for each category of the physically handicapped even though the estimated incidence of disability is 1.26 among the blind, 1.44 among the deaf and dumb, and 2.06 among the orthopaedically handicapped per 1000 persons according to the National Sample Survey Organisation (1973). The reservations are meant only for the physically disabled to the exclusion of the mentally disabled, some of whom are productive at different levels of competence. To this extent the existing provisions are discriminatory. The reservations are not applicable to private sector which employs a large proportion of the total work force. Likewise the class-A and class-B posts in the Central Government are excluded from the purview of reservation.

#### *Special Employment Exchanges*

The Government of India had set up special employment exchanges all over the country for the benefit of disabled persons. It has been the experience with the employment exchanges that vacancies notified by employers in the private sector show no preference for employment of the handicapped persons. The penetration of employment exchanges in general is low as only about ten per cent of the private sector recruitment is done through the exchanges (Gupte, 1976:17). In order to improve the chances of the handicapped, employers, covered under the Employment Exchanges Compulsory Notification of Vacancies Act, 1959, should be required to state whether handicapped persons are eligible against a vacancy; and this should be done through a suitable amendment of the rules under the Act. Most of the disabled persons registered with the special exchanges are not vocationally or technically trained with the result they are not easily accepted by the employers.

#### *Guaranteed Employment*

In tune with the philosophy of a welfare state, as a measure of social security, the statute book should have a law guaranteeing employment to all disabled persons, competent and capable of work, in open, semi-open, self or sheltered work settings. A model legislation needs to be evolved in this regard by the Central Government. For this purpose, the state resources could be augmented by levy of additional taxes and surcharges on: (a) private industrialists and commercial establishments; (b) professionals; and (c) estate property holders in urban areas—all at a prefixed percentage within the existing tax structure. The state may provide a matching grant for this purpose. A similar measure for rural poor is already in vogue in



Maharashtra, known as 'employment guarantee scheme'. Similarly, the organisational network for human resource development among the disabled persons needs to be considerably improved.

### *Apprenticeship Programme*

There is a need for training the disabled persons in suitable trades to improve their employability and to meet the growing need for skilled manpower in the country. An important pre-employment training scheme is apprenticeship training under the Apprenticeship Act, 1961. Under this Act more than 200 groups of industries have been notified and about 103 trades relating to engineering and non-engineering industries have been designated. Under this Act, it is a statutory obligation on all employers in notified industries to engage apprentices as per ratio prescribed in the designated trades. Under qualifications for admission in annexure I of the Apprenticeship Act, it is stated that a physically handicapped person, if declared fit, may be engaged as an apprentice in the particular trade for which he is fit.

It is estimated that in more than 50 per cent of the trades, disabled persons can be easily trained. The Union Ministry of Labour has issued instructions that, as far as practicable, taking into account the limitations of the handicapped individual as well as his prospects of securing suitable employment, three per cent of the vacancies of apprentices should be filled by physically handicapped persons. However, additional categories like the mentally retarded, leprosy cured and cancer disabled should also be accorded preferential treatment. The Seminar on the Training of Handicapped under Apprentices Act, 1961 and In-Plant Training in Industries held at Bombay in 1976 recommended: (a) reservation of seats for the handicapped, and (b) legislation to make it obligatory on the industries training them to absorb them as regular employees.

To improve the chances of employment for disabled persons, the Government of India needs to amend the Apprenticeship Act. Some points worth considering while amending the provisions of the Act are:

- (i) Selection of suitable trades for training of disabled persons, having regard to various types of disabilities;
- (ii) Fixation of ratio of disabled apprentices to the total number of apprentices in the designated trades;
- (iii) Duration of training;
- (iv) Amount of stipend to be paid during the training period;
- (v) Standards of physical fitness;
- (vi) Educational qualifications;
- (vii) Costs of additional equipment which may be necessary; and
- (viii) Role of social service organisations in training.



### *Labour Laws and the Disabled*

An analysis of the provisions of the labour laws in the country shows that laws like Payment of Wages Act, 1965; Payment of Bonus Act, 1965; Industrial Disputes Act, 1947; and Minimum Wages Act, 1948 do not apparently discriminate between the normal persons and the disabled persons. The Factories Act, 1948 contains provisions for fencing of machines, use of hoists and cranes, etc., aimed at promotion of safety, health and welfare of workmen in the factory. Commenting on the implementation of these protective provisions, the National Commission on Labour (1969:101) observed that the safety aspect is neglected by both the employers and the employees. Provisions for safety and prevention of disability also exist in laws relating to workers engaged in mines, plantations, dockyards, railways, etc. Victims of the disability are paid compensation under the Employees State Insurance Act, 1948 and the Workmen's Compensation Act, 1923. However, the labour laws do not approach the problem of rehabilitation in a comprehensive manner.

### *War Disabled*

Persons discharged from armed forces on account of disability are awarded 'disability pension' in addition to ordinary pension. The Directorate of Rehabilitation under the Ministry of Defence looks after the disabled ex-servicemen, specially in terms of placement in suitable jobs. Government has granted them relaxations in age for recruitment and reservations in government posts at all levels. However their problems need detailed study.

### *Laws for the Lepers*

Laws in many countries provide for special treatment, detention and restrictions on the movement of lepers. In India, lepers are covered by the Lepers Act of 1898. Section 6 of the Act empowers the state government to arrest without warrant pauper lepers.

In US, Sections 255, 256 and 301 of the Chapter on Public Health and Welfare provide for indigent lepers. These laws prohibit lepers from taking up certain trades, attendance in educational institutions, etc. In the UK, leprosy has been defined as a notifiable disease under the Public Health Act, 1936. The laws relating to lepers impose disabilities on the lepers in 'public interest' without adequate provisions for alternative care. As a result of prejudices, even completely cured lepers and their families and children are socially ostracised and barred from full participation in community life.

### *Problems of Mentally Disabled*

Mental disability presents manifold problems. Two major types of mental disability are: mental retardation and mental illness. The very nature of mental affliction may handicap an individual in transacting normal



communication with fellow human-beings, taking and acting on decisions, managing daily chores, and the disabled person and his family may have to cope with consternation, guilt, fear and misunderstanding. Legal provisions are of negligible utility as far as the social and emotional problems are concerned (McClellan, 1975 : 134).

Social legislation in vogue in India does not specifically recognise the 'mentally retarded'. The terms commonly referred to in the existing laws are 'idiot', 'lunatic' or a person who is 'mentally unsound'. However, these terms are not defined with precision. The Percy Commission in Britain described 'severely subnormal' in terms of persons with mental age below 7.5 to 9, or an I.Q. below 50-60. However, it was stressed by them that intelligence is not the sole criterion for judgment. There are instances where normal persons, in order to evade their contractual commitment, took refuge under the plea that they were of unsound mind when they entered into a contract.

#### *The Indian Lunacy Act, 1912*

This is the only law dealing exclusively with the mentally disabled in India. The Act is intended to protect the society just as in case of the Lepers Act. Under the provisions of the Lunacy Act, the police are empowered to arrest wandering lunatics. In the absence of special legislation for the mentally retarded, often the needs of the mentally retarded are confused with those of the mentally ill. The continuance of this obsolete law on the statute book of the country is a blot.

#### *Provisions in General Laws*

Many laws insist on soundness of mind as a precondition to be entitled to a privilege. To illustrate, a citizen ought to be mentally sound in order to be entitled to be a voter (Representation of Peoples Act, 1950; sec. 60). In a similar vein, even if a person has attained the age of majority, the contract entered into by him will still be void if he is of unsound mind as per section 12 of the Indian Contracts Act. Unlike the Mohammedan Law, the Hindu Marriage Act prohibits marriages where one of the parties is a lunatic at the time of marriage. However, the Hindu Succession Act, 1956 clearly states that unsoundness of mind is not a bar to inheritance of property. Chapter XXXIV of the Criminal Procedure Code deals with criminal lunatics. As per section 84 of the Indian Penal Code nothing is an offence which is done by a person who at the time of doing it, by reason of unsoundness of mind, is incapable of knowing the nature of the act or that he is doing what is either wrong or contrary to law.

#### *Guardianship*

The prevailing legal provisions relating to the retarded have a few drawbacks. The legal provisions do not make any distinction between various



grades of retardation and the concept of protection is judged by the criterion whether a person is wholly or partly incapable of taking care of his person and property. Regarding children, subsequent to the appointment of a guardian, there is no procedure whereby courts are required to make assessment at reasonable interval whether such arrangement of guardianship should continue. The crucial thing is to have someone who has a personal interest and concern for the retarded child and is capable of guiding and supervising the child properly. According to law, parents are 'natural' guardians. But it is better to designate someone as guardian for the disabled child to take care of the child after the death of the natural guardian, the parents, specially in view of the diminishing number of joint families. For this the parents have to move the court for appointment of a guardian (Baliga, 1976 : 35).

### *Trusteeship*

Despite the populist pronouncements and constitutional injunctions, we are yet to evolve a viable alternative to the system of social insurance for the disabled hitherto provided by the institution of joint family. As a consequence, a major anxiety of the parents is the future of their disabled child after their death. Questions such as, who will look after the disabled person with care and affection, and then for how long constantly linger in the minds of parents. To offset this, some western countries have introduced trusteeship schemes by insurance companies to provide care and comfort to the disabled person after the death of parents. In Ireland, a parent of a mentally retarded person wishing to join the trusteeship scheme has to take an insurance on his life and assign the policy to the National Association for the Mentally Handicapped of Ireland (NAMHI). After the death of the parent, the NAMHI will periodically assess the general welfare and needs of the retarded individual and provide him the necessary services and comforts. In UK and Sweden, even if a parent does not provide for, the state provides the necessary care and support for the retarded after the parent's demise. In India, the Federation for the Welfare of the Mentally Retarded has initiated action to evolve a trusteeship scheme for the retarded in India.

### *Legislation for Disabled: Global Perspective*

A global survey by the United Nations (1977) shows that there is an accelerating tendency among developing countries to enact legislation for rehabilitation of the disabled. In developed countries like Italy, New Zealand, Australia and France there is a tendency towards consolidation of the prevailing legal measures so as to ensure a more concerted approach to the problem of rehabilitation to encompass medical, vocational, educational and social aspects as part of a comprehensive rehabilitation programme. Together with legal enactments, implementation also is being decentralised





to the level of local governments.

The East European countries, viz., Bulgaria, Czechoslovakia, Hungary and Poland provide guaranteed jobs for disabled persons who have successfully completed vocational training programmes. In a majority of the West European countries a 'quota system' is in existence to compel the public services, industry and commerce to hire a certain percentage of the severely disabled. The legislation covers health care, pension system, and unemployment allowance. In U.K. and Poland, re-employ factories and invalid cooperatives are successful. Under the Handicapped Persons Assistance Act in Australia a financial subsidy is available towards the capital costs, equipment, and maintenance costs of establishing and running accommodation facilities as well as approved sheltered workshops, activity therapy centres, and handicapped children's training centres. Law No. 39 of 1975 in Egypt provides for a system of 'compulsory employment' (5 per cent of all employed persons) for qualified disabled persons in private and public sectors. In USA the Rehabilitation Act, 1973 provides for affirmative action, accommodation, recruitment and employee benefits.

The Law of June 30, 1975 in France ensures the highest degree of independence according to the potential of disabled persons. In UK, the Social Security Act, 1975 and the Social Security Pension Act of 1975 provide for four non-contributory benefits for the disabled: invalidity pension, invalid care allowance, housewives invalidity pension, and mobility allowance.

#### NEED FOR COMPREHENSIVE LEGISLATION

In India, there is an urgent need to formulate comprehensive legislation for the rehabilitation of disabled persons covering: compulsory registration of disabled persons; their vocational training; specification of suitable posts; their employment; protection of their working contracts; job counselling; employer counselling; payment of each benefit (if they are not provided with jobs at once); setting up of sheltered and social workshops for employment of persons suffering from severe impairments; obligatory and discretionary duties of the employers hiring the disabled persons including transportation and architectural modifications; financial incentives for the employers to engage disabled persons and the organisation of care for such persons; and the innovation of the agencies to plan, monitor and implement these programmes.

Besides, any legislation for the rehabilitation of disabled persons should consider, among other things, the following aspects:

- (a) Major declarations of world bodies. To illustrate, Declarations on Human Rights, the United Nations Declaration of the Right of the Disabled Persons, and the International Labour Organisation (ILO) Recommendation No. 99.



- (b) Guidelines of international agencies such as the Rehabilitation International, the World Health Organisation and the ILO, on prevention and rehabilitation of disabled persons.
- (c) Views of the national-level agencies championing the cause of disabled persons in the country.
- (d) Recommendations of empirical studies undertaken by schools of social work, governments and allied bodies, universities and other organisations.
- (e) The special needs and problems of disabled persons in rural and tribal areas of the country.

Special emphasis needs to be laid on enacting legislation for the protection of the disabled workers and their working environment and to provide for things such as easy means of access to the work place, sanitary facilities, technical devices and other equipment to make it more conducive to the handicapped to work. To reduce exploitation of the disabled workers, minimum statutory wages need to be fixed specially for workers in sheltered workshops and other production centres.

In the final analysis, no amount of legislation would be adequate, unless the preconceived notions and prejudices against the disabled are removed. This calls for a sustained and systematic campaign to cultivate positive social attitudes among the public about the abilities, capacities and potentialities of the disabled.

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## **A Comparative Study on the Congenitally Blinds and the Sighted on Tactile Size and Form Perception and Handedness**

**Miriam Ittyerah and Vibha R. Gupta**

THE SENSE of touch has been studied by sensory physiologists only as a passive or receptive channel, and has been treated as part of cutaneous sensitivity (Boring 1942; Geldard 1953) while neglecting its perceptual aspect. Katz (1925) and Revesz (1950) have argued that the hand is a kind of sense organ as distinguished from the skin of the hand. Their subsequent investigations in tactual discriminations and blind tactile performances, led Revesz to propose an unrecognised mode of experience called haptics, which involves more than the classical modalities of touch and kinesis.

The importance of the tactual modality is apparent, as in the absence of vision, a person can perceive the properties of the adjacent environment by touch. The blind utilise their tactual senses for most of the information about the world (Revesz, 1950).

A most significant break-through for the blind in the acquisition of tactual information was the invention of the braille system in 1829. The sense of touch has been employed as a means of communicating complex ideas especially since Louis Braille developed tactile pattern alphabets which enable the blind to read any suitably translated book or manuscript.

In psychological experiments, comparisons of tactual discriminations in the blind and sighted have been made in texture discrimination (Stelmagen and Culbert, 1963), force judgements (Nelson and Haney, 1968), two point and light touch thresholds (Axelrod, 1959, Heinrichs and Moorhouse, 1969), weight discrimination (Ahmad, 1971, Block, 1972), cutaneous localisation (Jones, 1972, Renshaw, *et al.*, 1930), size discrimination (Block 1972; Duran and Tufen Kjian, 1970), and curvature judgements (Davidson 1972). In general few differences are found in these studies, although the blind show some areas of advantage.

The role of experience in the ability to identify forms and patterns of objects has resulted in inconsistent findings in the relative abilities of the blind and sighted subjects in form and pattern perception tasks. Ayres (1966), for example, found that sighted adolescents performed significantly better than the congenitally blind in tactually identifying familiar objects; whereas



Foulk and Warm (1967) observed that the blinds were better than the sighted in judging simple raised dot patterns. Their findings may quite possibly be due to the similarity of these patterns to the braille format.

A larger body of research has used non-familiar stimuli, so as to control the advantage of either group with familiar objects. Davidson, *et al.* (1974) observed that the scanning strategies of the blind were more effective than that of the sighted group in isolating the distinctive features of three dimensional solid free forms. Berla and Murr (1974) reported that the most effective scanning strategy was the vertical scan when both hands are used than various horizontal strategies. Berla, *et al.*, (1976) observed that children who scanned in a regular way and attended to distinctive features of shapes were those who were relatively good at finding tactual shapes on a map. They emphasise that training in regular scanning and attention to distinctive features would improve map reading among the blinds.

In the light of these findings, the question of the educability of tactual functions is important but has received little attention. These findings should be encouraging to educators and others concerned with the blind, that performance is sensitive to training and experience. These demonstrations are only first steps in the implementation of scientific and systematic strategies towards education of the blind. It is extremely important for progress in this area to concentrate on the causes of events, rather than be content with a descriptive system.

With this in view, the present study was designed to compare the tactile size and form perception in the blinds and the sighted. Since the blinds depend on their tactual senses for most information, about the environment, the tactile modality is apparently more developed in them than in the sighted.

Therefore it was hypothesised that the tactile performance of the blinds would be significantly more accurate than that of the sighted when unfamiliar forms and sizes are used. Since both the groups were selected from the same university and the stimuli administered were unfamiliar, the sighted in this study served as the control group. They had no advantage over the blind as the stimuli were unfamiliar and visualisations were not easy. Besides, the effect of handedness on performance was observed in both groups. Evidence is not consistent as far as handedness is concerned. Lappivi and Foulke (1973) explained the possibility of having subjects use both hands. Hermelin and O'Connor (1971<sub>b</sub>) found an advantage with the left hand in braille reading children, most of whom were right handed, whereas Flanery and Balling (1979) indicated that the left hand was more accurate in tactile shape discrimination.

In the present study it was expected that the right hand performance of the right handed sighted group will be significantly more accurate than their left hand performance, whereas no such differences will be expected among the blinds, who use both hands in braille reading.



## METHOD

### *Subjects*

Forty volunteer students (20 congenitally blind and 20 sighted), from the University of Delhi, participated in the experiment. The ages of the subjects ranged between 19 and 24 years.

### *Stimulus Material*

Both forms and sizes, each consisting of a set of 5 stimulus materials (target stimuli) along with duplicates of the sizes and forms were administered to the subjects one at a time.

### *Forms*

Five, five sided, raised figures were constructed with ball pins closely arranged on 6×6 inches thermacol cardboards. All the forms had random shapes and the perimeter of each form was 25 centimeters. Duplicates of these forms were arranged on a 20×12 inches thermacol cardboard, so that the subject could match the target form with its duplicate. The 5 forms are presented in Fig. 1 on next page.

### *Sizes*

Five raised hexagons that differed in size were made from ball pins, that were closely arranged together. The hexagons were of the following sizes, 2, 2.5, 3, 3.5 and 4 cms. Duplicates of these sizes were arranged on a 20×12 inches thermacol cardboard. The 5 sizes are presented in Fig. 2 on page 203.

### *Design and Procedure*

The experiment is a 2×2×2 factorial design with repeated measures on the last two factors (Winer 1971, p. 540). The three factors are group, stimulus material and handedness.

The blind folded (sighted) subject was seated before a table and was required to trace a raised five sided form (target stimulus) with his forefinger. The subject's forefinger was placed (by the experimenter) at the top most corner of the form. As soon as a 'ready' signal was given, the subject was required to trace (feel) the form, in the clockwise direction with his forefinger and stop the tracing when the experimenter indicated. Immediately following, the duplicates were presented to the subject. The subject was required to trace a set of three duplicates that were indicated by the experimenter, and select the target stimulus from the set of three stimuli. The subject was allowed to trace the target stimulus and the set of duplicates only once. The instructions and the procedure were the same for the size stimuli.

The subject was required to trace each of the five form stimuli for recognition with his right hand. Each form was presented twice at random, there

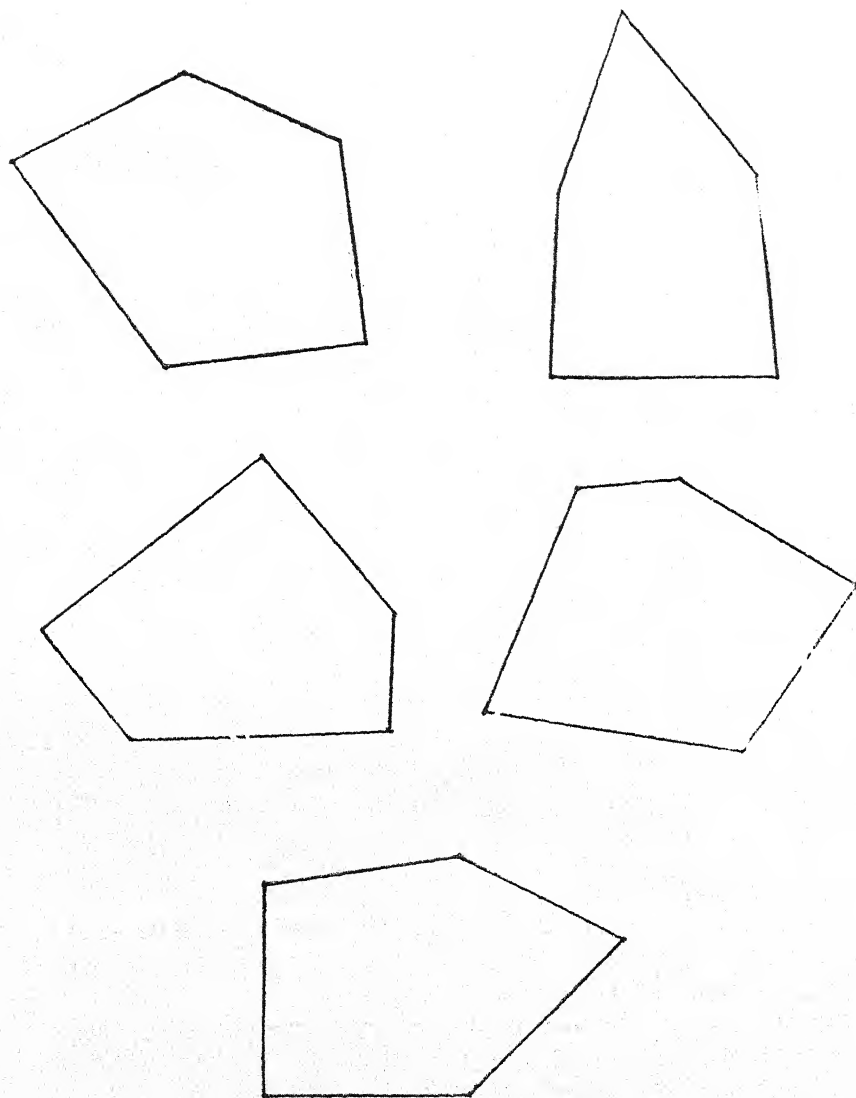


FIG. 1 five side forms.

being a total of 10 trials with the right hand. Then another 10 trials were taken with the left hand.

The size stimuli were then presented to the subject for tracing and recognition with the left hand, and another ten responses were noted, and finally these size stimuli were administered for tracing and recognition with the right hand. In this manner, 40 trials of one subject were noted. In order to control the order effects of stimulus material and handedness, the first five

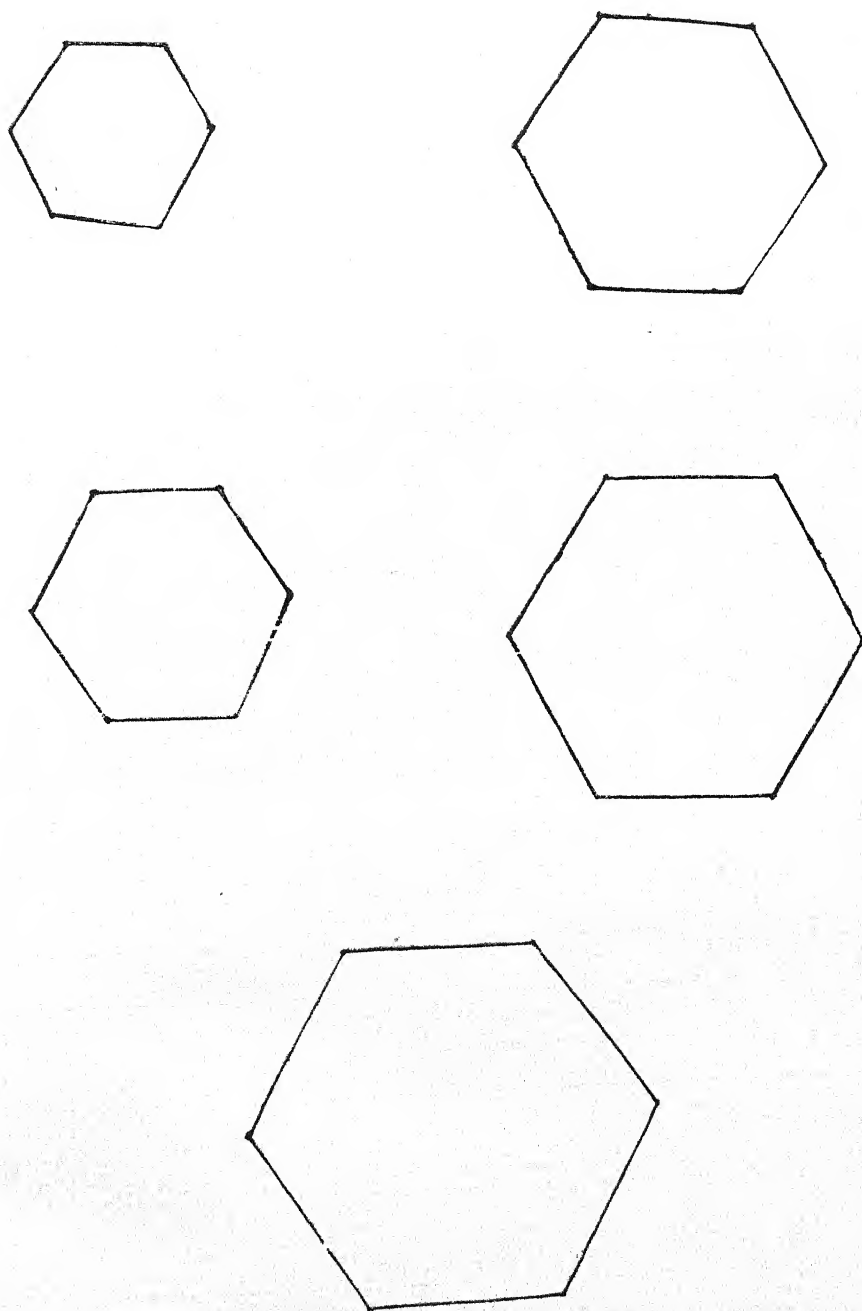


FIG. 2 five hexagons of different sizes.



subjects were presented with form, right-hand (FRA), form left-hand (FLH), size left hand (SLA) and size, right-hand (SRH). The next five subjects were presented with FLH, FRH, SRH, SLH. The next five subjects were given SRH, SLH, and FLH and FRH, the remaining five subjects were administered SLH, SRH, FRH and FLH. The correct responses were recorded and analysed.

The blind subjects ( $N=20$ ) were also given the same instructions and the experiment was counter balanced in the same manner.

### Results

A group  $\times$  stimulus material  $\times$  handedness analysis of variance on the correct responses indicated that the main effect of group is highly significant [ $F(1, 3) = 32.41$ ;  $P < 0.1$ ] indicating that the blinds and the sighted differ significantly in their tactile performance. The effect of the stimulus material is not significant, indicating that there are no form and size differences on the whole. However, the interaction effect (group  $\times$  stimulus material) is significant [ $F(1, 38) = 22.41$   $P < 0.1$ ]. This reveals that the two groups differ in their tactile performance with form and size stimuli. Besides, the effect of handedness has been found to be significant [ $F(1, 38) = 29.64$ ,  $p < 0.1$ ], although the group  $\times$  handedness interaction effect is not significant. These results show that although the right and left hand performances are significantly different, the two groups do not differ significantly on tactile performance with the right or left hand. The correct responses and means of the two groups in each treatment condition have been tabulated in Table 1.

TABLE 1 MEAN AND CORRECT RESPONSES WITH PERCENTAGE CORRECT IN EACH TREATMENT CONDITION

Group (A)	Stimulus Material (B)			
	Form $b_1$		Size $b_2$	
	Handedness (C)		Handedness (C)	
	Right $C_1$	Left $C_2$	Right $C_1$	Left $C_2$
Sighted ( $a_1$ )	X — 113	X — 90	X — 89	X — 67
	X — 5.65	X — 4.5	X — 4.45	X — 3.35
	% — 57	% — 45	% — 45	% — 34
Blind ( $a_2$ )	X — 127	X — 102	X — 134	X — 129
	X — 6.35	X — 5.1	X — 6.10	X — 6.45
	% — 64	% — 51	% — 67	% — 65

Table 1 indicates that performance of the blind group is markedly better than that of the sighted in all the treatment condition. Their accuracy is slightly greater in size perception (67 per cent) than in form perception





(64 percent). The sighted on the other hand perform better in form perception, although their performance on the whole is significantly less accurate than that of the blinds. These effects have been graphically presented in Fig. 3 and Fig. 4 separately, for size and form perception.

It can be noted from Fig. 3 that the accuracy of the blinds in size perceptions is greater than that of the sighted. However, both the groups perform better with their right hand. Fig 4 does not indicate such a marked difference between the two groups in form perception, although the blinds are significantly more accurate than the sighted. Here also, the right hand is more accurate in both groups.

### *Discussion*

Although the total performance of the blinds is significantly superior to that of the sighted, their keener perception with sizes is not a common finding. Moreover, contrary to expectations, the blinds, like the sighted, have performed significantly better with the right hand. This indicates that either the blinds, like the sighted, make use of a preferred hand, or that performance with a specific hand, on specific stimuli, is more facilitative. For example, Hermelin and O'Conner (1971b) reported that most right handed children performed better with their left hands on braille reading. Probably a change in the stimulus material may result in differential handedness performance.

The sighted group, on the other hand, although less accurate than the blinds in tactile perception, matched form stimuli more accurately than the size stimuli. One explanation for these findings may be that the sighted more frequently process information of colour and shape instead of relative size, since they are not visually handicapped to dimensions of colour and figure. It is possible that the blinds, on the other hand, due to their visual handicap, make relative judgements, *i.e.*, 'taller than', 'smaller than', etc., than judgements regarding shape. Hence, this may be one of the reasons for the improved performance of size matching among the blind. Moreover, since neither group was permitted any additional scanning of the stimuli, none had any advantage in multiple scanning. The scanning strategy of both groups on both types of stimuli was limited to one trace of the target and test stimulus. Therefore, the superior performance of the blinds is evidently due to experience in the modality.

There is little chance of visual imagery in the blinds, since all the subjects were congenitally blind. Besides, the sighted could not have benefited by visual imagery since the random forms and the different sizes were difficult to generate visually. Hence it could be concluded that the tactile performance of both groups was not mediated by codes other than tactile coding. Moreover, a growing number of findings suggest that tactual features of the input may be represented in memory. [Watkins & Watkins 1974, Hermelin and O'Conner 1971. Millar (1975 a, b) and Millar 1977].

In short, the question that motivated this study was whether the tactile

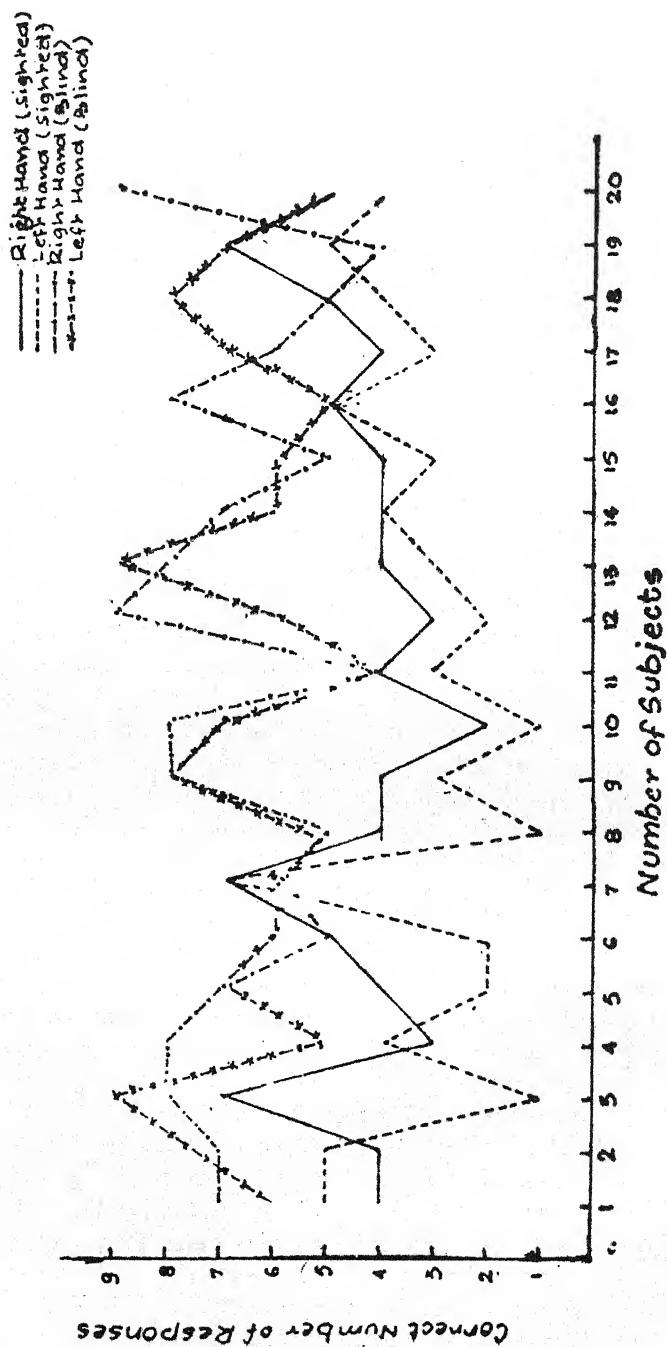


Fig. 3 Correct responses of each subject in the blind and sighted groups for size perception with right and left hands.

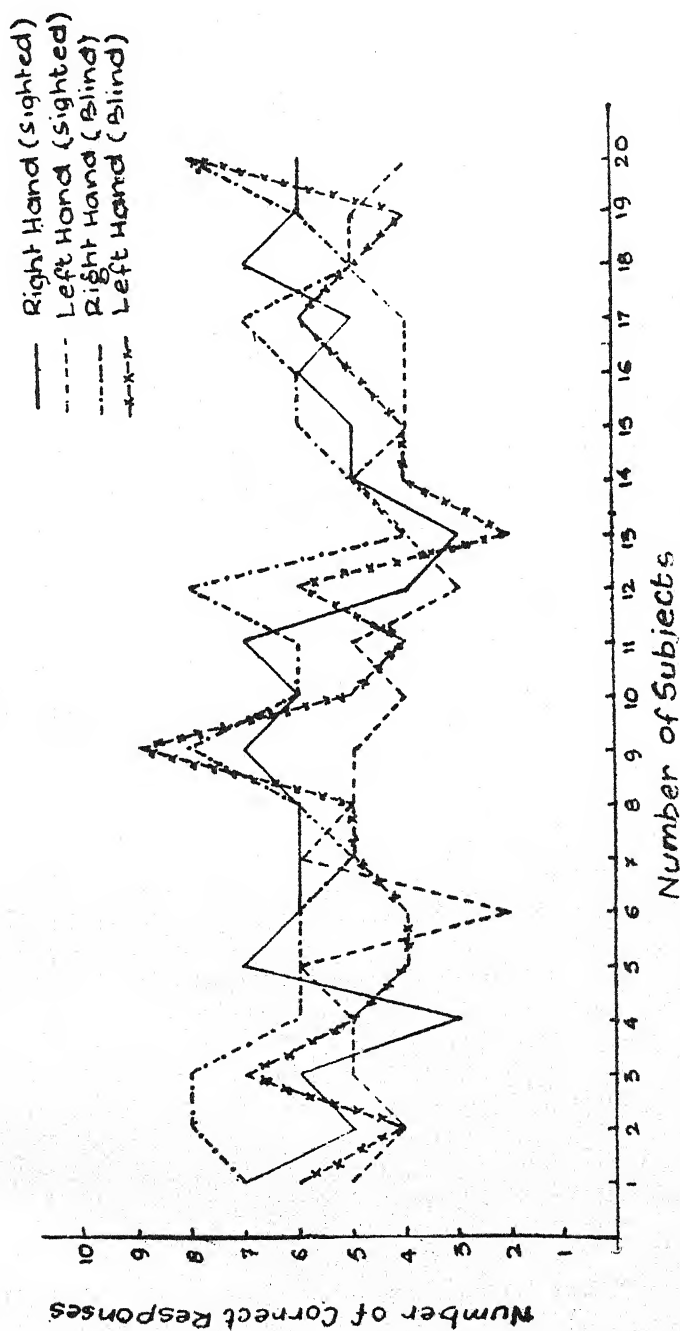


Fig. 4 Correct responses of each subject in the blind and sighted groups for form perception with right and left hands.



size and form perception of the blinds will differ significantly from that of the sighted. The findings of superior tactile perception and handedness among the blinds may be only another addition to the precious little research in this area. However, its relevance regarding the trainability of the blinds in tasks requiring finger and hand discriminations of texture, shape and size cannot be ignored.

According to the National Arts and the Handicapped Information Service the blinds constitute approximately 9 million of a total of 620 million people in the country. Diagnostic categories of the other disabled provided by the National Arts and the Handicapped Information Service are tabulated in Table 2.

TABLE 2 DIAGNOSTIC GROUPS OF THE HANDICAPPED IN INDIA

Total Population	620 million
Physically Handicapped	5-6 million with severe physical disabilities
Deaf	2.3 million
Blind	9 million
Visually Handicapped	45 million
Mentally Disabled	15 million
Institutionalised (Mentally Disturbed and Mentally Retarded)	20 thousand

Implicit in the above enumerated diagnostic groups are a few important ideas which can serve to orient our perspective. First among this is the simple notion that the basic condition is organic impairment, whether it be congenital, the result of physiological dysfunction or traumatic. While anatomical, physiological and neurological facts are of primary concern in medical diagnosis and treatment, they are also valuable in the psychological understanding of the physically handicapped.

The second important idea is that physical impairment may impose limitations on the person as well as reflect the limitations imposed, because of the socially and culturally defined reactions to him. It is apparent that status roles and adjustment for the physically deviant individual are tied up with social value judgements.

Surely some interest in the sensitivity of the tactual performances and handedness of the blinds may be beneficial to industries or other units that require the assistance of job hands in tasks where keen tactile perceptual capacities are a necessity. This will enable to promote employment opportunities for the blind, as well as fulfil the requirements of units where individuals trained in tactual functions are badly lacking.

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## **Vocational Training and Habilitation of the Mentally Handicapped**

**Nandini P. Divatia**

**I**T IS generally believed that the mentally retarded are not in a position to withstand the fast pace of industrialisation and technological development. But in fact we know from the experience of countries like the UK, the USA and Japan that though they have a highly developed technology, they have absorbed the maximum number of the mentally retarded in various industries.

The reason for this is that in these days of specialisation and technological development, though the final component that emerges from the factory may be quite complicated, if we watch carefully we find that some aspects of the operation are undertaken by automatic machines and that the others are of the simple assembly line kind. For example, in the electronics industry, though the mechanisms of radio, TV and telephones seem to be complicated, in many countries abroad, the maximum number among the mentally retarded are employed in the different sections of the electronics industry; for the individuals employed in these industries have to perform only simple repetitive work. In India also a workshop for the mentally handicapped (MH) at Bangalore undertakes the sub-contracting of assembly work of the Indian Telephones, Bangalore.

### **SPECIAL TRAINING FOR THE MH**

From experience of working with the retarded in a few workshops in India, we find that there are many industries and businesses where the services of the mentally handicapped may be utilised. Therefore, we assert that to rehabilitate the MH no special industry is required, but only 'specialised training' to help them to cope with their work or employment, and a willingness on society's part to help such persons by providing them with work and employment.

Dr. Henri Viscardi rightly says: "There is no such thing as the perfect ability or disability but only varying degrees of ability." This is very true of the MH. To rehabilitate them it is essential to design and plan training programmes in such a way that these varying degrees of ability and potentiality are developed to their fullest possible extent.



Mental retardation is a symptom of cerebral dysfunction caused by impairment in the brain cells owing to various diseases like epilepsy, encephalitis, meningitis, poliomyelitis, measles and jaundice, during the pregnancy of the mother, and also by accidents, genetic abnormalities, etc., occurring either after birth or at the development stage. Therefore, now-a-days the MH are also known as the 'developmentally sub-normal'. The degree of retardation depends on the severity of the disease or the developmental impairment. Thus the intellectual capacity has been underdeveloped from birth, hence the MH have never experienced normal development or normal intellectual ability. Therefore, any programme or treatment adopted to bring them towards normality should more appropriately be termed 'habilitation' rather than 'rehabilitation', because it is not a restoration of any capacity during a given life span. But, generally, along with other kinds of the handicapped, it is commonly referred to as rehabilitation. As there are varying degrees of retardation, any treatment, education, training or habilitation programme has to be planned according to the varying degrees of capacity. Therefore, psychologists and other social scientists have divided the mentally handicapped into three groups for the sake of convenience, but they are not rigid divisions. The performance and behaviour of a normal person or even an MH is never dependent only on his or her intellectual capacity, but on many other factors like emotional maturity, education, training and the social and cultural environment.

Those severely retarded are mostly below IQ 25 and have the intellectual capacity of a child of between two years to four. They cannot be educated nor trained in any skilled activity. They have to be trained to look after themselves, and most of them need custodial care if parents cannot manage them. Fortunately this category constitutes hardly 10 per cent of the total population of the MH. However, the majority among the public believes that all MH are of the same category, which is not true.

The second group of the MH is of moderate intelligence with an IQ ranging from 25 to 50. Their behaviour and performance are more or less those of a child of 4 to 8 years. They are not capable of formal education, but can be trained in many crafts and in simple repetitive jobs under personal supervision. Most of them can be made productive and can be rehabilitated in the best possible manner in a sheltered workshop, but are incapable of adjusting in open employment. This category constitutes about 40 per cent of the total of MH persons.

The third category is the best amongst the mentally handicapped persons with the IQ varying between 50 to 75. These people can develop and behave as a child between 8 years to 12 years. They are capable of receiving special education (up to level of IIIrd or IVth std.) and can learn routine, repetitive and semi-skilled jobs in many crafts and trades in a sheltered workshop under personal supervision. They are also able to perform similar jobs in open employment if suitable opportunities are provided to them. More than 50





per cent of the MH fall under this category. They can be purposefully integrated into society.

### THE SHELTERED WORKSHOP

Vocational training is the only method of educating and making the mentally handicapped economically and socially self-dependent, though the training given to each individual may vary. Therefore, a sheltered workshop has been defined by the National Institute of Workshops (USA) as follows:

A sheltered workshop is a work oriented rehabilitation facility with controlled working environment and individualised vocational goals, which utilises work experiences and related services for assisting the handicapped person to progress towards normal living and a productive status.

The sheltered workshop serves as a terminal place for the moderately retarded. They are paid wages for work done in the workshop. Most of these people are not able to adjust in open employment, hence they remain permanently in the workshop and work on various sub-contracted work received from various organisations, government as well as private. At present most of the workshops undertake training programmes in various crafts and trades like cardboard work, tailoring, weaving, carpentry, cane work, plastic moulding, screen printing and in various kinds of assembly work. After training, they receive sub-contract work in the same crafts or trades. It is encouraging to know that the bulk of the sub-contract work of preparing files, caseboards, re-caning of chairs, etc., is received from the government, the Bombay Municipal Corporation and some of the nationalised banks. This work is handled by the mentally handicapped in workshops in Bombay. They also receive sub-contract work for stitching napkins, pillow cases, weaving dusters, preparing plastic medicine bottle caps, greeting cards, etc. The same workshops serve as transitory places for the mild and a few of the moderate mentally retarded. They receive training in various trades and crafts and work on the sub-contract received. They can then be placed in open employment if they receive opportunities for performing similar work which they have learnt in the workshop. Thus many such trainees have been employed in open employment, at least in the big cities.

At present there are very few sheltered workshops which provide vocational training and also pay wages to the trainees for their work, and most of them are located in big cities. Hence it is very necessary to plan vocational training centres and sheltered workshops all over India in various states and in districts, keeping in view the existence of facilities for receiving sub-contract work from industries nearby and also having opportunities of employment in urban, semi-urban and rural areas. Therefore, programmes in each workshop should not be identical. In urban areas,



training should be provided in various trades and crafts, in simple repetitive work, assembly work, light engineering and semi-skilled work. In rural and semi-urban areas, training should be provided in small scale and cottage industries, agro-based industries like agriculture, horticulture, poultry, dairying, pottery, etc., so that the retarded from rural areas can find suitable employment in their own native environment. The mentally retarded are more suited and adjusted to cottage and small scale industries where a more personal and informal atmosphere prevails. In big industries they adjust much less owing to the more impersonal and formal environment.

In these workshops for the MH, training is not to be provided only in various vocations, but the inmates should also receive training in proper working habits, punctuality, discipline and social behaviour, in how to carry out orders from the supervisor, how to behave with colleagues. This is necessary because it has often been noted that after receiving training in a workshop, many amongst the mentally retarded lose their jobs, not because they do not know the skill pertaining to their jobs, but because of their behaviour and their inability to adjust to a new environment. To train them in all these aspects of an integrated personality, the workshops should have on their staff professionally qualified persons such as psychologists, social workers, technologists and trade supervisors. They also need supportive medical, psychiatric and family counselling services as well as facilities for sports, music, painting, moral hygiene, etc.

Careful consideration should be given to the following factors for imparting successful training :

1. Intensive training for a particular trade.
2. The machines and tools utilised should be simplified as far as possible with modifications and safety devices.
3. Instruction should be given only step by step.
4. Personal supervision.
5. Selection of a trade or a craft for training should be made only after evaluating a new trainee for his IQ, emotional maturity, aptitude and physical fitness.

The period of training should vary from person to person because their intellectual and emotional levels vary. The success of a performance is not always directly related to one's IQ but depends on such factors as emotional maturity, the attitude of parents and teachers, and other cultural factors.

The few workshops started at present to receive sub-contract work from various generous agencies; however, they also face many problems.

- (i) As it is primarily a training programme for teaching various crafts and trades, and not a manufacturing unit, the cost of production increases, which adversely affects receiving sub-contract work from



the government and other agencies. The government as well as private agencies should be liberal in accepting quotations from such training institutions as a social responsibility.

- (ii) It is difficult to get properly trained trade and craft teachers who have the aptitude and knowledge for imparting skills to the retarded persons. Training programmes for trade teachers should be organised with the cooperation of different industrial training institutes, departments of technical education and of various professionals such as psychologists, social workers, etc.
- (iii) The workshop authorities must ensure that the quality of the product is maintained when they receive sub-contract work. But the rate of production is likely to be low as the mentally handicapped are slow workers.

In spite of the many efforts made by social workers, rehabilitation officers, etc., it is extremely difficult to find suitable employment for all trainable MH. Hence, it is necessary to find other avenues for rehabilitation like 'self employment', and the 'home bound programme'. Some of the workshops have started providing training on these lines. But these programmes can be successful only if parents and guardians of the MH cooperate properly. This year, for the first time, one MH ex-trainee has received the 'best employee award' as a 'self-employed person'. He learnt recaning of chairs in a workshop and now recanes chairs in different offices. His investment for buying cane is less than Rs. 100. Another person is doing the business of a circulating library. He has invested some money in buying magazines, and he then circulates them in his area and provides home delivery.

A third person is selling stationery articles like files and letter pads, prepared in the workshop, to different offices where he has access such as to his father's friends, etc. These people are earning reasonably well. As they come from cultured, educated homes, their parents do not like them to work in a factory or a mill where they have to work with ordinary workers.

If the parents of the mentally handicapped cooperate and invest some money to start a small manufacturing unit such as stationery articles, box-making, etc., they can run a self-sufficient small-scale industry provided the parents arrange to receive orders, arrange for sales and look after the accounts. If they keep normal persons to the extent of 50 per cent in their unit, they can certainly run a successful, profit making small-scale industry, where normal as well as handicapped people can get employment. They can receive financial loans from the banks also. The government should provide incentives to employers for starting such units, where they can employ handicapped persons to half the total number



## APPRENTICESHIP SCHEME AND IN-PLANT TRAINING

In India, at present, there are very few sheltered workshops or vocational training centres; hence they cannot provide training in all those vocations in which the mentally retarded are likely to get employment. Moreover, these workshops are always facing with the problems of shortage of funds or space, with the result that they cannot equip their workshops for training in all vocations.

However, the experience of other countries teaches us that even if we have a well equipped workshop, the handling of the machinery and tools, the nature of the work, and the environment, both physical and social, are quite different in conditions of actual industry than in the workshop. The mentally retarded, therefore, take more time than normal persons in adjusting to new machines and to a different and rather impersonal environment. Therefore the development of inplant training is very essential for the mentally retarded.

The Apprenticeship Act, 1961, and inplant training in industries came into being to train normal people for various jobs, and the government identified 103 trades and recruited people for training in these various trades. In 1975 the Government of India announced a 3 per cent reservation of jobs in the public sector of industries for the blind, the deaf and the physically handicapped. Hence they became eligible for recruitment under the Apprenticeship Act, with suitable modifications. The mentally retarded, however, were not considered for the scheme as the specified trades were not suitable for them. The major hurdle was that they did not know how to select the mentally retarded as the capacity and performance of each retarded person varied. Therefore, those actively associated with the mentally handicapped felt that the jobs which the mentally retarded are able to perform in various industries and businesses either in urban or rural areas without any formal academic education, should be identified by a study group of professionally qualified persons such as psychologists, social workers, technologists, etc. This study should be undertaken with the co-operation of various industries and business houses.

Along with this identification of jobs, it is very necessary to develop a proper method of evaluating the performance of the MH by evolving a rating scale which can be termed as 'vocational assessment report'. This report should consider various factors like the IQ, emotional maturity, aptitude, physical fitness, motor dexterity, eye-hand coordination, etc., because the performance of the MH is dependent on all these factors. Various 'vocational rehabilitation centres' and 'industrial training institutes' started by the government can help in preparing vocational assessment reports. But this method of preparing the reports should be standardised all over the country, so that it becomes easy for any employer to judge the capacity of the applicant. This would not only help in



placing the MH under inplant training, but also help many organisers in planning the training programmes in many workshops, according to the needs of local employment requirements. If trainees are provided inplant training in various industries for about a year or so, they learn to utilise the tools and machinery of those industries and get adjusted to that atmosphere; then if vacancies arise they can be absorbed in permanent employment in that particular job in the industry concerned. Under the government scheme of Apprenticeship Act, 1961, if a physically handicapped person is employed by an employer under the inplant training scheme, the employer receives a Rs. 100 stipend for the trainee; which, in turn, he is supposed to pay to the trainee. This scheme should also be extended to the MH.

Many retarded individuals have been employed successfully in routine, repetitive and semi-skilled jobs, thanks to the efforts of some social workers and generous employers. Every year the best employee award for the retarded is awarded both at the state and national levels but, even here, the mentally retarded are not registered under the 'employment exchange for the handicapped' so as to be eligible for this award. This lapse should be corrected immediately. As mentioned earlier, a separate register should be maintained for the mentally handicapped stating their names, addresses and vocational assessment reports from the recognised workshops so that they might be recommended for suitable jobs. It is high time the government moves fast in this direction, otherwise the efforts made for the rehabilitation of the mentally retarded by the many voluntary organisations will be wasted.

### RESIDENTIAL INSTITUTIONS

When the mentally retarded are employed, they may need a permanent and comfortable place to stay for their whole life under supervision, as for various reasons it may not be possible for all of them to live with their family. Therefore residential institutions should be established, state and districtwise near their place of work, in both urban and rural areas. If such institutions are for the severely handicapped, they should be attached to a workshop where simple work operations like packing, pasting, gardening and the domestic chores and scrubbing can be taught, besides teaching them personal hygiene and managing their own affairs, seeing to their behaviour, etc. They can also help in the kitchen in their homes, and learn to stitch and mend their clothes. However, they have to work under constant and intensive supervision. This work is not remunerative in monetary terms, but has high therapeutic value which is very vital for developing them.

If these residential institutions are intended for moderate and mild MH they should be planned like a residential hostel for normal persons, where the inmates should be allowed to enjoy the liberty of managing themselves according to their individual and social competence, but under the super-



vision of qualified staff members. A terminal sheltered workshop, for the trainable retarded, should be located nearby, where they can work. Those who are absorbed in open employment should also be allowed to stay in these institutions, if they lack proper facilities for staying in their own homes.

These homes should provide various kinds of recreation and extra-curricular activities under the guidance of a qualified social worker. These activities should be developed as 'social clubs' for the mentally retarded, where they can enjoy various activities like music, painting and games. They should have a books and records library suited to their mental level. Occasionally, they should have a film show so that they can enjoy the company of like minded people and not miss their own homes. Such clubs could also be organised outside the institution by some of the service organisations like the Lions and the Rotary Clubs. MH persons who stay in their homes should be allowed to join such clubs. In these clubs they should be encouraged to invite some normal persons of their own age so that they can be integrated in normal society. Sometimes they should also be taken to various social functions outside their homes. When we plan for such integration it is advisable to restrict normal persons to a minority, otherwise the MH suffer from an inferiority complex.

Those handicapped persons who reside outside these homes should be allowed to stay there temporarily if they so desire. Some parents or guardians would like their wards to go and stay in these residential homes after their death or in the event of their not being able to look after them. They should be allowed to register their names in these residential homes whenever parents or guardians want them to. Arrangements could be made with insurance companies and nationalised banks that if parents invest a certain amount in the joint names of the trainee as well as the guardian, the bank can regularly pay a fixed amount for their maintenance directly to the homes. These homes should be managed by a board of trustees drawn from professionals of progressive outlook within areas like social workers, psychologists and financial, legal and medical persons.

#### GUARDIANSHIP

According to the declaration on the rights of the mentally retarded by the United Nations, the mentally retarded person has a right to a qualified guardian to protect his personal interest when he is not capable of doing so himself. The term 'guardianship' refers to a legally recognised relationship between a specified, competent adult and another specified person, the 'ward', who, because of his tender age or because of some significant degree of mental disability, judicially verified, is considered to lack the legal capacity to exercise fully some or all of the rights pertaining to adults generally in the country of which he is a citizen. The guardian is specifically charged with



protecting his ward's interests for certain purposes and exercising essential rights on his behalf.

The term 'guardianship' commonly means protecting the property or managing the financial affairs of the 'ward'. But in the case of the MH it not only means guardianship of property but of 'person' also. However well the institutions are managed by trustees, administrators, and professional staff, they have to look after the welfare of the whole group. Experience reveals nevertheless that everyone, whether normal or handicapped, requires some person who is interested in his welfare and guidance. Such a person can represent his ideas, likes and dislikes, select his way of life and attend to such needs as medical, personal, social and vocational care, the appropriate use of leisure time, and even offer advice on the selection of appropriate dress and the like. The guardian thus becomes a personal coordinator or decision maker to protect his ward's interest, but how much liberty or control the guardian should allow his ward depends on the maturity of the ward. Normally parents are the natural guardians. But parents should appoint someone of the same age who can look after the personal interests of their ward, whether he resides in an institution or at home, once the parents are dead. The guardian should visit his ward regularly and develop mutual trust in each other. He should know his ward's potentialities, shortcomings and needs. Thus he should guide him, giving enough liberty and gradually allowing him to make his own decisions. Such guardians can be appointed from within the family such as a brother or an uncle. Though this is a slightly complicated problem, it should be set within a legal framework to make it more effective.

MH persons, regardless of their degree of retardation, are capable of growth, development and learning at any age provided they are trained in a proper environment and by qualified persons. This requires many qualities on the part of workers and professionals working with them. Love and understanding are of prime importance. Dr. Maria Egg has rightly said that the mentally handicapped have to be trained to develop 'hand, head and heart.' It is said that 'love opens most impossible gates'. This is very true when we work with the mentally handicapped. Therefore, whether it is a school, a workshop or a residential institution, when selecting the staff, evaluating their personalities correctly is very essential. Emotional qualities and maturity should be given priority over intellectual qualities. Professionals or others should be motivated with a missionary zeal. Similarly a trustee or a guardian should also be selected very carefully. A high level committee of social workers, psychologists, financial and legal experts, medicalmen and spiritual counsellors could be set up. If the committee feels that any trustee or guardian is not up to the mark, it should have the power to change the person concerned.

Administration at all levels in such institutions should give priority to human, social and spiritual values which may be termed 'social adminis-





tration'. According to modern science, intelligence or brain may be a computer, but a 'human being' as a whole is never a computer. Whenever we deal with any human problem it becomes a problem of the interaction of social, psychological and spiritual qualities (positive or negative) and flows from a higher level to a lower level, like water. Therefore, success or failure in any human problem or human relationship is dependent more on personality qualities than just monetary or intellectual technology. Therefore, again, we often find that human relief work carried out by some of the spiritual organisations is more effective than the work of government officials or professionals.

Though schools, workshops and institutions for the mentally handicapped are very few in our country, the MH have successfully demonstrated their abilities and proved themselves productive and useful citizens. Most of these institutions have been started by voluntary agencies and are facing shortage of funds. Therefore their services are available only to a very small percentage of the total population of the MH in India. If we want to extend these facilities to all of them, then the government should share their major responsibilities. At present, as the law stands, any MH is still an 'idiot', according to the Indian Lunacy Act of 1912 even though we have seen that many lead productive and purposeful lives

#### SUGGESTIONS FOR REFORM

We hope at least that in this International Year For the Disabled the government will initiate the following reforms which should be supported by appropriate legislation for the total rehabilitation of the MH:

1. The government should provide land and generous grants to voluntary agencies which are prepared to establish schools, workshops or residential institutions for the MH. This should be encouraged in all states, in districts and in rural areas, so that there is a complete network of institutions all over the country.
2. The apprenticeship scheme and inplant training which has been extended to the deaf, blind and the physically handicapped, should also include the MH with the same stipend. If necessary, suitable trades for the MH can be introduced as an extension of the scheme.
3. The Ministry of Labour and Employment should help in undertaking a survey of identification of jobs with occupational analysis of each job which an MH is capable of performing. This can be done with the help of vocational training centres and various sheltered workshops of the MH and through suitable industries.
4. Vocational rehabilitation centres started by the government for the physically handicapped should help to prepare 'vocational assessment reports' for MH persons.



5. Employment exchanges for the physically handicapped should have a special officer on duty who can keep a complete record of mentally handicapped persons along with their 'vocational assessment reports' so that he can help to place many retarded persons.
6. Recently, the Government of India announced the reservation of 3 per cent jobs in 'C' and 'D' categories in both the public and private sectors for the blind, deaf, mute and physically handicapped. Similarly, the government should reserve 5 per cent of all simple, repetitive and semi-skilled jobs which the MH are capable of handling under the 'identification of jobs' for the mentally handicapped.
7. Small and cottage industries and agro industries should be provided with some incentives like tax exemption, lower power and water rates, and concession in raw materials for employing mentally handicapped persons in suitable employment.
8. Financial aid and credit facilities under the DIR scheme should be provided by the nationalised banks, financial corporations, etc., for developing sheltered workshops either by voluntary agencies or industrialists, for developing self-employment or home bound programmes for the MH.
9. The MH should be granted concessions for rail and bus travel. As the physically handicapped receive 50 per cent concessions in petrol charges, so institutions providing transport facilities for the mentally handicapped should receive 50 per cent concession on petrol and diesel charges.
10. The government should provide complete financial assistance for undertaking any survey, research or feasibility studies, and for providing technical assistance, information regarding product specification, market, capital demand, financial planning, etc.
11. The government should provide incentives to the public and private sectors for providing suitable sub-contract work to the workshops for the MH. These workshops should be able to obtain raw materials at concessional rates when the materials are used for training purposes.
12. Certain government departments like the Ministry of Labour and Employment and the department of technical education should provide free guidance to the workshops in negotiating their contracts.
13. In the same way as for ordinary people, the state should take the responsibility for providing free education up to the primary level and up to the age of 16 years to all MH children preferably in special schools.
14. Well planned social security schemes and guardianship schemes should be evolved to provide social and legal protection to the interest of the MH.



An eminent lawyer, Mr. Nani Palkhiwala rightly says: "No laws are perfect in themselves, unless they are interpreted and implemented with good understanding and with a noble motive, otherwise the laws can be misused also." This needs due consideration and thought while formulating the laws for the retarded.

The habilitation is complete only when we can make the lives of the MH happy by looking after all aspects of their lives—physical, mental, economic, social, emotional and even spiritual from the cradle to the grave. This can be done successfully only by the combined efforts of the government, local bodies, industrialists, the business community, professionals, social workers, parents and, finally, the retarded themselves.

Expenditure incurred over such progressive schemes is sure to pay cumulative dividends not only to the retarded but also to the productivity and social and economic development of the whole nation. Such schemes are therefore of prime importance in a welfare state.

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# Integration of the Blind with the Sighted

**Sushma Batra**

**I**NTEGRATION IS very difficult to define as it is a value loaded term. But most of the social scientists want to define integration in empirical and non-normative terms. However, it has been defined variously by sociologists, psychologists and economists. Even within the same discipline, authorities differ in regard to its definition.

Sociologists often try to define social integration in positive, non-residual terms; for example, Parson conceives of integration "as coherence of roles and functions in terms of a common or central value system". But the psychologists admit the impossibility of defining it in positive terms. They believe that there are no positive indicators of integration at all. In society one finds disorganisation in various forms and integration implies 'absence of disorganisation'. Economists do not agree with the view of both these disciplines. They say the primary basis of social stratification in modern communities is economics. It is the economic condition which determines the kind of education that a person is likely to receive and consequently the range of choice of occupations. Once a man's occupation is determined, his mode of life and his social status are fixed to a large extent. Thus the harmonious relation of all parts of a social system results in 'integration'.

## WHAT IS INTEGRATION?

Combining the views of all disciplines, the term 'integration' has been defined in the International Encyclopaedia of Social Sciences, according to which, the term integration refers to a process whereby the quality of relations among autonomous social units (kinship group, tribes, cities, trade unions, trade associations and political parties) changes in such a way as to erode the autonomy of each and make it part of a larger aggregate.

Taking this definition as the base, the various disciplines modify the term in the context in which they want to use it. By integration of the handicapped a social scientist means the handicapped becoming a part of society and participating in its social and cultural activities on the basis of equality. When the handicapped people are not regarded as a class inferior to or different from the non-handicapped and when they are treated as normal human beings, in having some physical disability and yet capable of



functioning as responsible and contributing members of the community, then only can we say that they are fully integrated into society. The ultimate goal of rehabilitation is to integrate them fully into society in this manner. The present paper has been restricted to one class of the handicapped, *i.e.*, the blind.

For this purpose, a workable definition of the term 'integration' has been attempted. Integration of the blind with the sighted can be achieved by minimising among the sighted and the employers the existing prejudices and misconceptions regarding the blind and by instilling self-confidence among the blind and providing them with opportunities to work/study with the sighted and thereby increasing the communication of the blind and the sighted to the maximum possible extent.

In India because of misconceptions regarding the capabilities of the blind and the religious belief that blindness is the result of bad deeds committed in the past, it is customary to treat the blind either with pity or rejection. The provision of protective measures to enable them to be integrated within the general society was not realised until recently.

Since independence there have been tremendous changes in India both in the direction of our thinking and in the structure and functions of our social organisations. The constitution of India lays down the establishment of a socialist democratic society with a welfare state as the goal of our endeavour.

As a result, a number of educational/vocational institutions for the blind were opened at the Central or state level as well as by a number of philanthropists and voluntary organisations. But, in spite of concerted efforts of so many, the sighted have not yet accepted the blind at par with them. The society is still not fully prepared to accept the working/studying of the blind and other groups of the handicapped with normal persons. This fact is very clear from the written life experience of Prof. Mahindra Krishna Kumar, a blind professor of the Calcutta University. When he was searching for a job, an employer once told him: "When we are getting finished goods in the market, why take damaged ones?" Thus, the need of the hour is to find an insight into the various causes of the unsuccessful integration of the blind with the sighted.

#### MICRO STUDY OF INTEGRATION

The author undertook a study of the integration of the blind persons with the sighted as part of her university studies. It aimed at analysing the factors which increased or hindered the integration of the blind with society. As the study aimed at integration, the population of those blind who were studying/working with the sighted constituted only a minority of the blind. A problem thus arose as to how to select a representative sample of the sighted persons. The nature of contact of the sighted with the blind was



considered an important factor, influencing the attitude of both towards each other. Proper care was taken in this study to select those sighted who had come in contact with the blind and, separately, a representative sample of the sighted, from the general public, who might or might not have come into contact with the blind. The five selected strata comprised of students, factory workers, office workers, self-employed and the unemployed. Thus, occupational status was taken as the stratification variable. A representative sample of blind respondents was taken from each strata. This was matched with a sighted counterpart. The total sample size comprised of 60 blind and 60 sighted persons.

Another category of the sighted respondents was taken from the general public. Taking educational status as the weight, the percentage of the general public falling within each strata was known. Then a representative sample of 100 persons was drawn in proportion to their corresponding educational status. The aim was to study the awareness among the general public about the capabilities and limitations of the blind. Lastly the opinion of all the employers (22) of the blind employees included in the study was sought on the employability of the blind within their organisations.

From the study it became apparent that there are some obstacles which make it very difficult for the blind to achieve their 'total' integration into the society.

#### FACTORS THAT HINDER TOTAL INTEGRATION

The physical disability, *i.e.*, loss of sight, greatly affects the outward appearance of a blind person. Because of his disability, he looks different from others and therefore is ranked as a separate class. He is often segregated from his playmates, because he is not considered fit enough to play with them in a normal way and to compete with them on equal terms. Moreover he is sent to a separate school especially meant for children of his 'type'. These greatly reduce their chances to come into contact with normal children resulting in their social segregation.

The physical disability of the blind is not the only factor. The greatest hurdle in their integration is the several prejudices or misconceptions prevalent among the general public regarding the handicapped. These are caused by the ignorance of the public of the capabilities of the blind. This ignorance went down with the increase in their educational status. But that was not the main source of change; instead, the contact of the sighted with the blind acted as the major reason for making the attitudes of the sighted more positive. The blind population is relatively small in number and, as a result, very few people get the chance to have personal contact with them. Thus the irrational attitudes of the public towards the blind are not so much due to any kind of hostility or ill-will but it arises from the people's lack of knowledge about the problem—the needs, the capacities and also the after effects of



disability. All these account for unrealistic attitudes, misconceived notions and a lack of sympathetic understanding about the handicapped people. The study revealed that it is not only the general public, even the relatives of the affected, their own mothers, in most cases, either reject or over protect them. In addition to these social barriers, some psychological reactions felt by a majority of the sighted towards the blind also obstruct their social and cultural integration, such as pity, fear, repugnance, anxiety, etc. These reactions are either expressed verbally or become known by gestures and actions.

#### THE BLIND THEMSELVES ADD TO THEIR WORRY

It is not that only the sighted people are responsible for the segregation of blind persons; sometimes the blind themselves are contributing agents. With changing time the blind are undertaking higher education and are working as any other sighted person in factories and offices, etc. As their educational status increased they have become more economically independent; the blind resent the feeling of pity as it touches their personal dignity and hurts their self-respect. Therefore they deliberately avoid those who show pity either by words or actions. This creates a psychological chasm between the blind and the sighted making their integration difficult.

After identifying some of the major obstacles to 'total' integration of the blind with the sighted, the study puts forward suggestions to promote the process of integration:

1. Since it may not be possible to impart education to all or to bring all the sighted in contact with the blind, it would be worthwhile to give correct information to the public regarding the problems, needs and capacities of the blind. To achieve this aim, the use of mass media like the press, the radio, television, and films may be made. Through this, the achievements of the blind may also be shown so that the sighted learn to appreciate what the blind still possess.
2. The blind should be encouraged to avail the opportunities of education and training in schools/institutions along with the sighted. This early contact of the blind with the sighted will not give them the feeling of being different from the sighted and, on the other hand, the sighted also will not develop the attitude of pity towards the blind. As far as possible the trained blind persons may be helped in getting employment in the open sector and along with that they should be provided accommodation with the other sighted individuals, instead of forcing them to live with other blind as segregated halves.
3. The blind persons should be encouraged to participate in social and cultural activities along with their sighted friends. The study revealed that with the increase in economic independence, the blind celebrated cultural and social functions more frequently in the





company of the sighted than with their blind friends alone.

4. Lastly the blind should be made to realise that their social and cultural integration is not possible without their own effort. They should be helped to accept their physical disability in a realistic manner in order to overcome its effects to the maximum possible extent. They must strive to promote their social integration into society by all possible means.

The study thus concludes that there are no pre-determined factors which increase or decrease the integration of the blind. The main efforts in this regard have to be put in by the blind themselves. Even in the sample under study, the integration proved most successful in cases where the blind had self-confidence and retained their will power for integration. The educational status, the occupational status, and contact also acted as contributing factors but the principal factor remained the self-confidence of the blind themselves.

While aiming at integration we must not lose sight of the fact that the whole social order is geared to suit the needs and abilities of the able-bodied and this puts the disabled to a great disadvantage not because they are intellectually inferior to the former but simply because they are physically disabled. This restricts their opportunities to achieve education, employment and rightful social status. Therefore it is an obligation on society to provide special facilities to the disabled to increase their chance to compete on equal terms with the non-handicapped persons for obtaining education and gainful employment. Providing special facilities to the blind would not constitute a preferential treatment; it would rather be an equalising treatment which is a must to enable the disabled to have equal opportunity.

In keeping with this objective, the General Assembly of the United Nations proclaimed 1981 as the International Year of Disabled Persons. The theme of the year is 'full participation and equality'. In other words, it means that integration should replace the present trend towards segregation. The Government of India endorses the objectives set forth by the General Assembly. It is hoped that with the end of the year 1981, the aim of integrating the disabled with the able bodied will not come to an end, instead it will mark the initiation of the efforts towards integration.

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## **Rehabilitation of the Mentally Retarded— Problems and Suggestions**

**G N. Narayana Reddy**

**T**HE MENTALLY retarded person is an individual who is fundamentally the same as a normal person, but only operating at a lower level of intelligence. He is a person, who from birth or from very early age, is lacking in intellectual endowment. He lacks in general alertness, initiative, creative attitude, sentiments and ideals. He lives by habits and may learn by rote. In simple words, he can be described as a person who was possibly behind the doors when the Almighty was handing out intelligence.

As a result, the degree of self-sufficiency from the point of view of his economic and social level happens to be at a much lower level. He is slow in developing compared to the other persons of his own age. Because of his limited capacity and dependency he becomes a victim of his own environment. In this sense, he comes to be identified as an individual who is unable to guard his rights or accept responsibilities. Moreover, various hurdles, social, political, legal, psychological and physical come in the way of restoration and reinvestment of privileges of the retarded. Prejudices develop and colour the attitudes and actions of people towards them, stigmas develop, the retarded come to be identified as individuals who are unable to guard rights or accept responsibilities. Since the reason for this is the fact of his being different, disability becomes a minus factor, a handicap, a stigma.

### **PSYCHOSOCIAL PROBLEMS OF STIGMA**

Purely from the psychosocial point of view, stigma is preceded by three stages in human relationships—prejudice, discrimination, segregation or isolation. Prejudice is a hostile attitude created by judgement, based on certain fixed norms. This is followed by discrimination which refers to overt acts committed against individuals and groups because of prejudice. Segregation is a special form of discrimination whereby the handicapped person or group is denied of certain privileges enjoyed by the rest of the society, like access to common facilities. Prejudice is the most important motive force which results in discrimination and segregation.



Of course, it often follows that the people who entertain prejudice are themselves victims of insecurity or frustration. Again, prejudice in a person evokes resentment in the person about whom he is prejudiced. The two hostilities interact upon one another gathering mass as they go and, in course of time, become set behaviour patterns. The prejudiced person and the victim of his prejudice are both manifestations of social disorganisation.

Stigma is the extension of the prejudiced behaviour to its extreme where there is a blind desire to mark the object of prejudice, so that he will forever be recognised as abnormal and unnatural.

The degree of stigma varies from country to country and, in the same country, from area to area and from community to community. In communities with little contact with modern civilisation, stigma has been found to be absent or negligible. In a community in which there are many mentally retarded people there is less stigma attached to the handicapped than in those where the handicapped are few. There is more stigma attached to handicaps which are inexplicable. In some communities, only those with gross disfigurement or deformity may be isolated, the lesser may be blemished or ignored.

So rehabilitation of the mentally retarded is a complex and continuing two-way activity, wherein the retarded have to be trained to become members of the society and the society has also to reorient its thinking towards the retarded. The process of rehabilitation incorporates changes and movements—a handicapped person's ability to perform meaningful work changes; his physical and mental capacity changes; his attitude changes; his life style changes; he changes.

The dictionary meaning of 'habilitation', is to 'furnish with working capital or quality for office', and to 'rehabilitate' means 'to restore privileges, reputation or proper condition'. Thus rehabilitation is both restoration and reinvestment of human resources and working capital. Both the processes are applicable to the retarded, depending on the condition for which the retarded and the normals have to be closely involved in this operation. Wolman (1977) interpreted the meaning of rehabilitation as a set of services and activities designated to help the disabled people to achieve optimal adjustment. In the field of mental health, rehabilitation has been defined by Freedman, *et al.*, (1975) as a concerted attempt to order the environment, so as to compensate or at least to minimise the residual social and psychological difficulties, to take advantage of the patient's assets, and to develop or redevelop his skills. The traditional forms of psychiatric treatment concentrated on personality reorganisation and resolution of intra-psycho conflict. Today, the treatment is more concerned with increasing the functional capacity of the patient, so that he may lead his life as normal as possible. 'Habilitation' and 'rehabilitation', rather than 'cure', have become the organising goals of many treatment efforts.



## WORK THERAPY

In fact, rehabilitation is usually considered as a fourth phase in medicine (promotion being the first, prevention the second and care the third). The term is now being stretched to include the whole range of health problems including psychiatric disturbances and the problems created by alcohol and drug dependence and mental retardation.

One of the most important findings in recent professional advances in the field of mental health is that there is no necessary single connection between the presence of psychiatric illness and the ability to work. This is different from many physical illnesses where rest and abstinence from physical activity are important part of the treatment. In this sense employability of the mentally ill involves some of the same questions as employability of workers suffering from physical disabilities. This has been very well demonstrated by the works of Akabas and Winer (1969) and Sommer (1969). Through a focussed clinical programme, hundreds of workers suffering from some form of mental illness were helped to maintain themselves on their jobs or to return to work after absence for treatment.

Though the individual units in rehabilitation have become more and more specialised, rehabilitation service itself is a valuable and necessary part of the general health service in which the promotive aspect of rehabilitation comes into play. Rehabilitation service is also becoming a professional group service, a multi-disciplinary team approach, as in house building. Following this realisation, most countries now have created at least one active rehabilitation institution which could serve as a standard prototype for the nation.

A more recent development in rehabilitation is the stress on the economic aspect. Economic independence, based on productive capacity, however marginal, gives the handicapped person a sense of self-respect. Thus, the concept of disability, prevention and rehabilitation would seem to have two goals, reflecting two sets of values: (a) to prevent; to reduce it with treatment if possible, and to develop the patients' residual activities to the highest possible level in the case of long term and permanent retardation; and (b) to make it possible for as many rehabilitated people as possible to get gainful employment and also reduce the cost of institutional care.

## THE FAMILY AS A BASE OF REHABILITATION

Foremost among those who must be prepared to carry a significant burden of habilitation or the rehabilitation programme are the parents of the mentally retarded. With love and sympathy they can help their children to achieve nearly complete independence during early life, leading to adult security and emotional stability. It is absolutely unrealistic to think that a retarded person's behaviour is the direct result of his handicap. He is as



much a product of his environment as any normal person. Parental attitudes play an important role in the success or failure of the programme. Parents who understand, accept and work with their child can be of great help in encouraging, stimulating and strengthening his efforts to make a full use of his abilities, whatever they may be. Also, they bring to the child the much needed environmental experiences that are immensely valuable in helping him to gain control of his social, educational, and psychological preparations for life. It is often noticed that the retarded are either over-protected or neglected but are seldom understood and given opportunity for normal development.

### VOCATIONAL FACILITIES

Vocational rehabilitation depends on many factors other than just the intelligence of the retarded. Moreover, in the present highly industrialised society, job opportunities exist for all levels of ability or skills. Purely repetitive routine operations can be successfully performed by the stable mentally retarded with measured intelligence level of about 5 years. Therefore, many such mentally retarded can become partially or wholly self-supporting, provided they have been properly trained and placed in suitable jobs and they are given the necessary aid, supervision and protection by parents, relatives and friends, and provided they are not handicapped by personality disorders or serious sensory or motor defects. If they are helped in understanding their limitations, interests and capacities and taught through concrete meaningful experiences, they can be made productive workers. Parents, however, must recognise the limited achievement potential of their children and reconcile themselves to their limited goals. The retarded have definite potentialities. They have some specific ability particularly in certain arts, which if developed, can make them self-supporting.

Thus the early introduction of counselling and guidance programmes to the members of the family is bound to be much more effective than at a later stage when behavioural pattern of the retarded has been established. By becoming productive workers, they can help themselves, their homes and the society at large. Parents must realise that it is of less importance whether their living conditions are humble or the kind of work they do is simple. The status of the family should not be considered as supreme. The main aim should be to train the affected to perform their work and at the same time to learn to live their simple lives.

In general, the mentally retarded worker needs more understanding on the part of the employers than the family. If this is available, an excellent response is obtained. New jobs must be very carefully explained and administered; once the method and idea are grasped, one can be quite sure that instructions will be carried out accurately for an indefinite period. The affected person lacks in adaptability and thus cannot be switched from one job



to another without preparation. Therefore, in a country like ours, barring a few selected mentally retarded, it may not be possible to build up any open employment. It is not always possible to have sympathetic employers and protective environments that the affected need.

Moreover a huge surplus manpower adversely affects employment prospects for the disabled. It is, therefore, absolutely necessary that we must establish sheltered workshops to prepare them for a useful role in society. Such workshops can assess their abilities and strongly motivate them; they can also play a vital role in training them to develop their work habits, work tolerance, coordination and productive speed. In these types of workshops it is not only the actual job which is taught but also specific job habits and proper attitudes required of the workers. Because, if the retarded is to achieve remunerative employment, the development of the appropriate work behaviour is necessary. Various follow-up studies in other countries have indicated that jobs are lost by the retarded very frequently because they lack appropriate work behaviour and not because they lack the specific skills required for the job. More over the retarded are often induced by the undesirable elements in the work unit to take part in anti-social activities. Sheltered workshops in some cases are used as interim placements, still a job is secured outside. In most of the cases, the retarded are kept in the sheltered workshops permanently. These workshops can train the inmates in jobs like labelling, assembling, inspection, tracing, cutting and sewing. Research carried out in other countries indicates that the retarded have been successfully employed in unskilled or semi-skilled work such as delivery boys, cleaners, simple machine operators, repair servicemen, labourers, liftmen, night duty clerks, garage helpers, tradesmen, workers in hotels, hospitals and firms, car washing, parking attendants, laundry workers, shop boys, messengers, packers and folders.

#### SUGGESTIONS

In a recent national workshop on rehabilitation of the mentally disabled conducted by the NIMHANS, in March 1981, as part of a programme of the International Year of the Disabled, it was suggested to the government that:

1. In this International Year of the Disabled, among the disabled the mentally ill also should be included, along with the mentally sub-normal.
2. All mental hospitals and psychiatric centres in the country should start rehabilitation programmes in their hospitals, including adequate arrangements for family involvement in the programmes.
3. There should be an adequate number of mental health workers in all such centres.



4. There should be adequate facilities for in-service training for all mental health workers.
5. There is need for adequate after-care facilities for discharged patients from hospitals, like half-way homes, day-care centres and patients' hostels.
6. Vocational rehabilitation centres for the mentally disabled should be started with organised vocational training on scientific lines.
7. Sheltered workshops should be established and where feasible, are to be combined workshops for all disabled and not just for the mentally disabled.
8. Certain items of consumer nature/light engineering electronics should be identified by the Central Government and exclusively reserved for manufacture by sheltered workshops/rehabilitation workshops started by hospital/social welfare organisations.
9. Orders should be issued to the effect that Central / state government departments/public sector undertakings/government aided institutions should buy their requirements for the identified reserved items only from such workshops.
10. Large industries, both in public sector (both Central and state) and private sector, should reserve a minimum of 2 per cent of their light engineering assemblies from their present and future expanded capacities for sub-contract to sheltered workshops.
11. All manufacturing/sub-contracting industries established for the rehabilitation of the disabled should be exempted from taxes and government should ensure supply of all essential and scarce raw materials and also concessional finance from banks for running these units.
12. Incentives by way of 100 per cent tax exemption should be made available to all sub-contracting industries from all earnings as a result of sub-contracting to sheltered workshops.
13. Voluntary agencies/organisations should be involved in the rehabilitation programmes.
14. Tax exemption should be given for all donations to the rehabilitation measures of the disabled.
15. To the job reservation quota of 3 per cent to the disabled, a 1 per cent quota should be added for the mentally disabled.
16. Family pension should be extended to the families of the mentally ill.
17. Subsidised transport facilities and travel concessions should be provided as it is being provided for the physically disabled.
18. Free medication should be provided in the hospitals for the needy patients.
19. Special schools for the mentally sub-normal and special teachers in such schools should be organised by the government.





20. A separate cell should be established in the health directorate of Central and state governments for the rehabilitation programmes for the mentally disabled.
21. Social welfare departments should have a separate directorate for disabilities which should include mental disability also.
22. There should be adequate provision for mental health education programmes through various mass media, to educate the public about mental disability and its prevention.
23. A national institute should be established for research and training of mental health workers in the rehabilitative aspects of the mentally disabled.

Further, it is most urgent to tap sources in the community like the religious mutts, charitable institutions and big agricultural forms to rehabilitate these persons under the care of qualified clinical workers in case a large number is being absorbed. This is feasible because the majority of our retarded persons hail from agricultural families and they would be in a better position to work in such settings which mainly require routine practices.

In his book 'Social Barriers to the Integration of Disabled Persons into Community Life' S.D. Gokhale has pointed out that it is also necessary that certain barriers like lack of public identification with the rehabilitation work; inadequacy of funds and volunteers; the handicapped person's fear of the society and his preference of his own kind; insufficient education and training facilities and job opportunities for the handicapped; difficulty in getting married; irresponsible writings in the press about the handicaps; fatalistic attitude towards both handicapped and rehabilitation—all this should be taken care of by social action.

In a country like India where economic resources are meagre, it is absolutely essential that rehabilitation should be made as simple as possible and should be made cheap and easily accessible to the common man. The whole network of supporting services like medical care, schools and paediatric centres, should be established all over the country and research in the area of rehabilitation should be encouraged. Of late, there have been some good signs in these directions both in India and elsewhere.

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## Policy and Planning for the Deaf

**Surrender Saini**

**S**CIENTISTS, PSYCHOLOGISTS and educationists have conducted research in different fields of human welfare but few realise that the basic social and economical needs of the handicapped do not differ from those with normal physique or intellect. This understanding is essential for making any programme for the disabled. The needs and problems of the disabled have no geographical limitations. Hence the UN decision to celebrate the International Year of the Disabled Persons.

The planning of welfare programmes for the handicapped persons is mostly on an *ad hoc* basis in this country because there is no reliable data yet available about them. According to the Government of India sources the number of the handicapped people is about 10 per cent of the total population and there is an average annual increase of about 40,000 among them. It is estimated that out of the 10 per cent, about 1 per cent would be the deaf, which means, on a rough estimate, they are 6.84 million.

Therefore, it is very necessary that urgent steps are taken to collect data to ascertain the magnitude of the problems of the deaf. Also, no welfare programme for the physically handicapped can succeed unless it is a joint endeavour of the government and voluntary agencies and the community at large.

Realising the plight of the handicapped, the Government of India has fixed a 3 per cent quota of jobs for them in government departments and public sector undertakings. Out of this 3 per cent share, 1 per cent is reserved for the deaf. But this decision is not being fully implemented. Many of those entrusted with the responsibility of rehabilitating the deaf, turn a deaf ear to their claims. Jobs, reserved for them, are kept vacant on the plea that suitable qualified disabled persons are not available. This is an unhelpful attitude.

### **AD HOC PROGRAMMES**

It has been observed that the response of the private sector organisations is more encouraging in this regard. They are more willing to give the disabled persons an opportunity to show their worth. The employers are by and large happy with the deaf and other handicapped people because of their undivided



attention to their work.

Some undertakings have set up special cells for the employment of disabled persons and have sought the cooperation of voluntary organisations, like the All-India Federation of the Deaf, in finding suitable disabled persons for various jobs under them.

As already mentioned, absence of reliable data is a handicap for proper planning for the education, training, employment and other facilities for the disabled. So far all programmes are on an *ad hoc* basis.

Economic rehabilitation of the deaf is very important. They have the capacity to learn to work, to undertake responsibility, to act as disciplined soldiers, dedicated workers and enlightened citizens of the country, provided they are given the requisite opportunities. They have proved to be better workers in offices as well as factories.

There are at present about 117 schools for the deaf and they are run both by the government as well as voluntary organisations (47 by government and 70 by voluntary organisations). Speech and hearing centres are about 18. The Government of India has set up 13 special employment exchanges for the physically handicapped. There are six teacher training centres.

There are about 45 voluntary organisations working for the deaf at the national, state and district levels. But not even the tip of the iceberg has been touched.

The available services are confined to urban areas. The vast rural population has not been touched. The 'deaf' is considered as curse in the family. So he rots and invariably dies an unnatural death. He neither gets medical aid to arrest deafness, if possible through medicines or hearing aids, nor education to be able to earn for himself.

#### PREVENTION OF DEAFNESS

To arrest deafness there is an imperative need of a vast network of centres for early detection, diagnosis and treatment. Equally important are suitable steps to prevent deafness which is due to many factors. Maternity and child health centres as also the primary health centres must cater to this aspect of the health problems.

Like free and compulsory primary education for normal children up to 11 years, there has to be arrangement for the education of the deaf. There may be integrated schools and/or special schools depending on the prevailing conditions in different areas. Vocational training will equip the deaf to be able to earn not only for themselves but also for their families.

Employment does not mean only 'service' in government or private agencies. There are vast avenues of self-employment after proper training; for example, photography, tailoring, carpentry, leather tanning, printing and so on. For self-employment the prerequisite is a place for work and



loan/grant on reasonable terms. Reservation for work places is very necessary to enhance this scope of employment.

The government has framed a national plan of action for the disabled since India is one of the signatories to the resolution proclaiming 1981 as the International Year of the Disabled Persons. A national committee has been set up under the chairmanship of the Minister for Education and Social Welfare. The committee has drawn up a national plan of action and the same committee will review its implementation from time to time.

Specific objectives to be achieved by India within the framework of the general objectives declared by the United Nations, in the light of its present resources, would be to evolve: (a) a national policy on the disabled to include educational training; (b) employment measures to achieve full social integration; (c) protections and guarantees under the law; (d) to prepare a perspective development plan for a comprehensive rehabilitation service; (e) to initiate practical programmes that would carry immediate benefits to the handicapped people; (f) integration of the handicapped people in the community; (g) inculcating among them the sense of self-dependance while leaving the care of the institutions; (h) to give a positive rural bias to services for the handicapped in order to avoid uprooting of any individual from his native environment; (i) to develop and put into operation a comprehensive programme for the prevention of disabilities through legislative sanction where necessary; (j) to prepare a base for research and development through the national institution, etc.; (k) to make rehabilitation programmes of the handicapped responsive to the future changes in the social/economic climate and development of techniques bearing on this field; (l) to develop publicity service regarding the employment potential of the handicapped and campaign to eradicate social prejudice; and (m) to collect all relevant data on the handicapped in the country.

The programme includes developing a nucleus of services for the young disabled children under 14 years of age and extension of work opportunities in various settings to disabled people.

The Ministry of Social Welfare has been suggested to take action for establishing at least six centres in the country to carry out differential diagnosis of disabilities in respect of children under 14 years of age; offer advice; care at home and placement in schools, etc.; to devise schemes for encouraging integration of young handicapped children in ordinary schools; scholarship schemes to cover a part of the cost of their education, and training of teachers with a view to improving the standard of teaching of young handicapped children.

#### EMPLOYMENT FOR THE HANDICAPPED

In the field of employment, vacancies should be reserved for disabled persons in all sections of the economy by legislation or otherwise. Steps



should be taken to promote the establishment of sheltered workshops employing handicapped people and provide financial assistance to organisations running such workshops in all states, if possible; to provide special concessions in terms of finance to cooperatives set up by handicapped people; to offer technical guidance and loans at preferential rates of interest for self-employment of handicapped people; to evolve a scheme whereby aids and equipments needed by the handicapped people for employment to be provided by the state; and concessions like conveyance allowance, readers' allowance for the blind, escort allowance to paraplegics, etc.

Programmes should be prepared for the prevention of physical and mental disabilities in addition to blindness. There should be examinations of consanguineous marriages which often lead to the birth of disabled children. And a programme of mental health should be undertaken for schools for prevention of emotional disturbance among school going children.

Special technical institutions should be established by the states or voluntary organisations to impart training to various categories of handicapped people. At least 2 per cent vacancies should be reserved for them in the industrial training institutions, etc.

Rural programme includes sending of teams of specialists to impart rehabilitation training to handicapped people in their homes in rural areas, establishment of workshops or cooperative societies engaged in agro-based industries by suitable agencies and to arrange for special itinerant teachers to offer special help in literacy programmes for the rural handicapped children.

Under the national plan of action, a national council is to be set up permanently, consisting of representatives both of government as well as voluntary agencies in the field to advise the government on all matters concerning the handicapped. A sample survey of the handicapped population is to be initiated, works of the handicapped should be considered for various honours awarded by the government and a scheme be evolved for giving awards to handicapped people who have distinguished themselves in various walks of life.

Primary emphasis in research programme, under the national plan of action, should be on widening the occupational choices and improved strategies of education, scientific study of the advantages and disadvantages of the dynamics of integration, the identification of problems in integrating handicapped children in rural schools, research and development of technological aids and home equipment, to assist handicapped persons in agricultural and allied operations, study of ways of overcoming communication problems and developing strategies for eliminating social factors in disablement.



### LEGISLATION FOR THE HANDICAPPED

So far, India has virtually no legislation concerning the handicapped. Presently there is need for a special Act to deal with the disabled persons of all categories and employment. Legal protection to safeguard all interests of the disabled is a dire necessity.

Deafness is a handicap which is not visible. So, not much has been done for them so far. In many cases, deafness can be prevented if there is proper health check up of children in early ages. Among 600 children of age group from 0 to 6, in certain parts of Delhi, the actual health check up conducted by the Delhi Social Welfare Advisory Board with the help of the Delhi Medical Association, under the pilot project 'Family Through the Child' has revealed that more than 32 per cent children suffer from ear problems, 1.3 per cent suffer from mental retardation, 10.6 from trachoma, 30 per cent from worm infestations, 22.5 per cent from recurrent diarrhoea, 21 per cent from recurrent chest infection and 15 per cent from skin infections. Regarding immunisation the least said the better. Immunised against small pox is 32 per cent, 18 per cent given BCG, 8.66 per cent given TAB and not a single child out of 600 given full doses of DPT and polio.

The above factual information speaks for itself. How much emphasis has to be given on preventive, curative, and rehabilitative aspects can be well realised. This is a challenge to society and it has to be met by the government and voluntary organisations by working in close cooperation and cordial relationship.

□



## A Note on Rehabilitation Aids

**K. Raghunath**

A NEW era in rehabilitation in India started when a team of experts from the World Health Organisation undertook in 1963 a detailed study of the problems concerning India's requirements of rehabilitation aids. The team's recommendation was taken into consideration by the Government of India and thereafter the Artificial Limbs Manufacturing Corporation of India (Alimco) was incorporated in November 1972 under the chairmanship of Dr. B. Sankaran.

The Corporation was registered under section 25 of the Companies Act. The finances of this venture were obtained from the National Defence Fund. The factory went into production in October 1976.

### OBJECTIVES

This venture has the following objectives in meeting India's rehabilitation aids:

(a) A design team of Indian experts, after a detailed study, would evolve indigenous designs for manufacturing and it was decided that Alimco would follow the module concept as developed in advanced countries. The advantages of a module concept are:

- (i) Reducing time considerably for fabrication and fitment of orthotics/prosthetics to the disabled.
- (ii) Ensures quality of products, standard and uniformity.
- (iii) Facilitates mass manufacture and so helps in bringing down the prices.

To carry out the manufacturing activities, a modern plant was established in Kanpur, equipped with sophisticated plant and machinery. Production is planned in a scientific manner and as a back-up for production the factory has a well equipped modern tool room. A quality control department adequately equipped with testing facilities ensures that the products conform to specifications laid down by the Indian Standards Institution and international standards.

- (b) India is a vast country and to reach the limb fitting facilities to



remote places, it is essential that limb fitting centres are established at different locations of the country. To commence with, it has been decided that 6 regional limb fitting centres and 28 peripheral limb fitting centres would be set up along with the existing medical colleges. These centres are assisted by Alimco by providing them cash grants, technical know-how and products.

Alimco is now in a position to render consultancy to any foreign country for setting up of limb fitting centres.

(c) To meet the growing demand of highly skilled prosthetic and orthotic technicians and bio-engineers a modern training-cum-fitting centre with clinical facilities is set up at Bhubaneswar under the name 'National Institute of Prosthetic and Orthotic Training' (NIPOT). Here training is also given to orthopaedic surgeons on the use, techniques and procedures in the fitment of orthotic/prosthetic devices. NIPOT trains 20-25 bio-technicians every year along with two short courses of 4-6 weeks duration for orthopaedic surgeons.

(d) In our country no regular organised research and development efforts have been undertaken so far. To obviate this and facilitate our own research and development, setting up of a rehabilitation engineering research and development unit under Alimco has been approved by government in principle.

With the meagre resources available with Alimco, our engineers are engaged in active development efforts to continuously improve the existing products and bring out new ones.

#### KANPUR PROSTHETICS CENTRE

The Corporation has also a limb fitting centre in its own factory premises primarily meant as a clinical unit for trying out its products and also to meet the local requirements of the disabled. To make the products of the Corporation available at reduced rates to the needy people, certain lateral arrangements and actions with charitable organisations have been arrived at.

#### SALES

Price of the Corporation's products is comparatively low to that of equivalent products abroad. Still it is too high to be afforded by the disabled persons in India as 90 per cent to 95 per cent of them belong to poorer sections of the society. Therefore the sales off-take has been poor. The Government of India has issued a memorandum in which the need for providing artificial limbs to government employees free of cost was accepted. What is to happen to non-government employees? We presume that further government orders will soon be issued providing a major subsidy in the



prices of artificial limbs. With the subsidy, the off-take is expected to improve and we hope that in due course the subsidy needed would also decrease.

We were able to compete in global tenders and were successful in securing orders from UAE, Zambia and Libya. More enquiries are coming in from other parts of the world.

Assistance on any of the aforesaid objectives may also be provided by Alimco. We have already trained students from developing countries. Our products are also being accepted by countries abroad in larger quantities.

### PLANS AHEAD

A large number of the disabled in our country are affected in the lower extremities, so it was decided that priority would be given to the manufacture of orthotic/prosthetic modules pertaining to the lower extremities. This has been taken in hand and completed. Subsequent to this, Alimco would be developing sophisticated products of the following nature:

- (a) Myo electric appliances.
- (b) Hydraulic and hydro-pneumatic appliances.
- (c) Sensory aids for the blind and deaf.
- (d) Electrical wheelchairs with electronic controls and others.
- (e) Environmental engineering.

In this International Year of the Disabled Persons, the Ministry of Social Welfare has sanctioned Rs. 18 lakhs to the Corporation to subsidise provision of aids to disabled persons during the year. Under this scheme 100 per cent subsidy is given to the disabled whose total income is below Rs. 750 and 50 per cent subsidy is given to disabled persons whose income is Rs. 751 to Rs. 1500 per month. We hope that a small beginning has been made and our government, alive to the needs of the disabled, will give us more funds for supply of our products to the disabled at subsidised rates.



## National Sample Survey of the Disabled in India

J.N. Tewari

WHILE THE National Sample Survey Organisation (NSSO) had collected some estimates of the number of handicapped persons per one lakh population in 1973-74 and released it in their journal *Sarvekshana* no systematic attempt was made to collect comprehensive information about the incidence or impact of disability.

With a view to fill this critical gap in information, NSSO has launched from July 1, 1981, a countrywide sample survey of disabled persons. The survey is suitably designed to throw information on the magnitude of the problem of disability, its probable causes, and the extent of facilities available for treatment, aids and economic rehabilitation as well as deficiencies felt by the beneficiaries. Information is being collected on visual, communication, and locomotor disabilities which manifest in a person as blind, deaf, dumb, or orthopaedically handicapped. In addition, data is also being collected on social adaptation, developmental milestones and behaviour of children in the age group of 5-14. The survey would cover both the rural and urban areas of the country.

In this nationwide survey programme, the NSSO is canvassing a central sample and the state governments are participating by taking up at least a matching sample. In the central sector 6,022 sample villages and 3,964 urban blocks will be covered while 6,968 sample villages and 4,756 urban blocks will be covered in the state sector. A stratified two stage sampling design has been adopted for the purpose of selecting the sample. By and large, each district has been treated as a stratum (except for a few districts in Gujarat where parts of the districts belonging to different regions are treated as different strata). Some districts, with very low urban population, have been merged with the neighbouring districts to form an urban strata. The census villages in the rural areas and urban blocks in urban areas constitute the first stage unit of sampling. The samples allocated to different states/union territories are selected with probability proportional to size in the rural sector and at random-without replacement in the urban sector.



## HOUSEHOLD SURVEY

The second stage unit of sampling is the household. The households in the villages urban blocks are stratified into two categories: (i) households with at least one disabled person, and (ii) households without any disabled person. A complete enumeration of all households belonging to the first category is taken up for detailed investigation while from the second category a sample of households from the remaining households is selected in a systematic way for enquiry into social adoption, developmental milestones, and behavioural pattern of children of the age group 5-14 years. In all about 1.2 million households are being covered in the survey.

The survey operation is being taken up by the specially trained staff of the NSSO and state governments and will be completed within six months. The primary investigation is undertaken by a team of well qualified and trained field investigators who visit the selected sample villages and blocks, collect the desired information through the process of personal interview of the sample households and record the details in a structured schedule of the survey. Adequate arrangements have also been made for field supervision and scrutiny of filled-in schedules in the field and at the desk, to ensure qualitative aspects of data collection. After proper data processing and tabulation the survey results are expected to be released in 1983.



# The disability syndrome

The physical and mental impairments suffered by many of those we call disabled need not incapacitate them from becoming full members of society if the right kind of attention is paid to their needs. It is important, therefore, to understand the concepts of "impairment", "disability", and "handicap", and the relentless escalation people undergo from one condition to another.

## IMPAIRMENT

"Impairment": a missing or defective body part; paralysis after polio; diabetes; mental retardation; nearsightedness.



### Prevention

- ★ Medical: vaccination against communicable diseases such as polio; effective antenatal and neonatal care, with special attention to high-risk pregnancies.
- ★ Social/economic: alleviation of poverty; nutrition education; higher overall education level; improved food distribution.
- ★ Environmental: design of safer buildings and vehicles; traffic legislation; public health standards at workplace.

## DISABILITY

"Disability": difficulty in seeing, speaking, hearing, writing, walking, conceptualizing, or in any other function within the range considered normal for a human being.



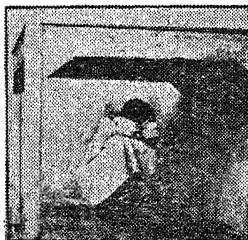
### Prevention

Some kinds of "impairment" inevitably lead to "disability", such as congenital deafness. Others can be prevented from doing so by early treatment, or reversed.

- ★ Medical: availability of medical services, and early treatment of diseases such as trachoma; psychiatric services; nutritional rehabilitation; health campaigns.
- ★ Social/economic: attempt to change negative social and cultural attitudes towards impairment; vocational counselling.

## HANDICAP

"Handicap": a "disability" has interfered with the development of ability to do what is normally expected at a certain age.



### Prevention

Measures preventing escalation to a condition of handicapping can also be thought of as curative and rehabilitative.

- ★ Medical: physiotherapy, speech therapy; provision of prostheses and orthoses
- ★ Social/economic: special education; early stimulation for young child; braille, lip-reading, sign language; employment and sheltered workshops; public education campaigns.
- ★ Environmental: removal of architectural barriers; provision of transportation.

## LEGISLATION IS NOT ENOUGH

In the advanced countries, the current economic slump has thrown some 17 million people out of work, but no group is having a tougher time in the tight job market than disabled men and women who often are the first fired and last hired.

In some places, their rate of unemployment is twice that of able-bodied persons. Because of sex bias, the situation is doubly difficult for disabled females.

Experience has shown that protective legislation which aims at promoting employment of disabled people can help but that it is no panacea. In the United Kingdom, for example, the quota system has proved to be relatively ineffective in a depressed labour market situation.

Designated employment and reserved jobs programmes, even if implemented, provide little relief. Moreover, the jobs in question are usually menial, low-paid and of low status.

ILO specialists say that legislation concerning employment of the disabled will have a better chance to be effective if it were more flexible and formulated in such a way as to stimulate private and government initiative.

—From ILO



## **Surveys of the Handicapped—Abroad**

### **Australia**

The Australian Bureau of Statistics (ABS) is currently doing a major survey on disability in Australia. This survey will be completed only later this year. However, it is generally recognised in Australia that approximately 10 per cent of the population has some form of major disability; about 50 per cent of the people over 60 have limited mobility and about 75 per cent of the people over 75 are disabled in some way. It is also surmised that for every person killed on the road another 30 are injured.

As can be expected, the proportion of population suffering from some form of disability is increasing with the growth in population, increase in life expectancy, improved social conditions, nutrition, and medical care. Just who, where, and how these people are disabled will become evident only when the results of the current ABS survey are obtained and analysed.

Australia also has defined disability as the other countries have, and there are several medical practitioners in the country who look for the abilities of their patients rather than to their disabilities. In Australia, as elsewhere, the disabled people are as varied in their needs and life styles and the emphasis of the country's policy is on achieving good health and preventing disabilities.

The Human Rights Commission Act, 1981 has received royal assent and this will permit the establishment of the Commonwealth Human Rights Commission and one function of the Commission, it is anticipated, will be to investigate and report on matters concerning the constitutional rights of the disabled persons in Australia. Anti-discrimination legislation to protect the disabled now exists in three Australian States, *viz.*, New South Wales, South Australia and Western Australia.

#### **ON-GOING SERVICES**

There are many on-going government services and programmes in Australia to the disabled people, although they have not been established specifically for IYDP. For instance, under the Commonwealth department of Social Security, there are programmes such as rehabilitation schemes for handicapped people; invalid pensions; handicapped child's allowance; and financial assistance to organisations providing certain services to disabled people, such as sheltered workshops and activity therapy centres.



Besides the Department of Social Security, the other Commonwealth departments providing programmes of help to the disabled are the health, education, and the veterans affairs departments, each with its own responsibility.

The state governments also provide a wide range of services and assistance. In relation to IYDP, the Australian activities are coordinated by the Minister for Social Security, with the National Advisory Council on the Handicapped (NACH) and the Standing Inter-Departmental Committee on Rehabilitation (SIDCOR) coordinating the Commonwealth Government's input and the Australian Council for Rehabilitation of the Disabled (ACROD) coordinating the input of non-government agencies. All states and territories have a minister each responsible for coordinating IYDP activities.

The Department of Employment and Youth Affairs (DEYA) is concerned with formulating schemes to provide access to employment for the disabled. The DEYA objective is to place more disabled persons in employment and training and to ensure that they are given equal opportunity in the labour market. This will be done by conveying the message to employers that there are many jobs that can be done just as readily by a disabled person as by a non-disabled person.

#### DISABLED JOB SEEKERS

As at the end of June, 1980, there were about 28,000 registered job seekers in the country classified as disabled. Adult males accounted for 67 per cent of all disabled job seekers (registered) compared with 12 per cent adult females, 12 per cent junior males, and 9 per cent junior females. As high as 43 per cent of the unemployed disabled job seekers were from metropolitan areas.

The categories of disability for unemployed disabled job seekers at the end June 1980 were:

	<i>Per cent</i>
Orthopaedic	38.5
Mental Retardation	9.1
Respiratory	7.6
Mental Illness	7.5
Disorders of Heart, Circulatory System and Blood	6.8
Organic Nervous Disorders	5.7
Hearing and Speech Difficulties	4.0
Gastro-Intestinal-Renal	4.0
Blindness or Other Visual Handicaps	3.7
Alcoholism	3.5
Not Listed Above	9.6
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There is no obligation at present for industries in Australia to employ disabled people. However, employers are discouraged to stand down workers on account of disability. Under the new anti-discrimination legislation in South Australia, New South Wales and Western Australia, it is illegal to discriminate against a person or a prospective employee on grounds of disability.

The role and services of the voluntary organisations in Australia are both varied and extensive. They provide as many as 15 basic types of services from accommodation and library facilities to medical services and activity centres. These voluntary agencies work both at the city level as also at the local level.

An important feature in the planning for IYDP in Australia is the inclusion of and consultation with the disabled people. The objective is to use 1981 to work towards providing for disabled people the same opportunities, acceptance, choices, personal insurance, and dignity enjoyed by the rest of this community. The catch-phrase in Australia ensuring full participation and equality (the UN motto) for the disabled is 'break down the barriers'.

*—Compiled from Information Made Available  
by Elizabeth Lucas, Director, IYDP Unit,  
Melbourne.*

## Ecuador

Surrounded by a craggy park outside, the house in Calle Garcia Moreno in Quito, Ecuador, was an unlikely place to choose for a vocational rehabilitation centre. Yet the institution that started here is on its way to becoming a model for others in Latin America.

Six years ago, when the International Labour Organisation was first asked to develop rehabilitation services in Ecuador, it estimated that 300,000 men and women of working age were physically or mentally disabled. Since then 8,000 more have been added to the list each year as a result either of illness or of accidents—often occupational accidents.

The pace of industrial development, fuelled after 1972 by newly-exploited oil resources, inevitably brought with it an increase in the numbers of work-disabled Ecuadoreans. Believing that they should be helped to become again productive and contributing members of the community, the government asked the United Nations Development Programme to finance a rehabilitation scheme to be set up with the help of the ILO. Now that the project has successfully wrapped up its international phase, ILO adviser, Ricardo Cereda Montes, from Argentina, can look back with satisfaction on the results of the uphill job he undertook.

Finding and keeping instructors was the first hurdle.

"Vocational rehabilitation was an unfamiliar idea and at first we had



very few candidates", says Mr. Cereda. "There is in Ecuador only a trickle of graduates in some specialised fields such as psychology, social work, occupational and speech therapy."

Problems did not end once an adequate number of instructors were found for the seven subjects taught initially—metalwork, carpentry, sewing, shoemaking, leatherwork, office work and ceramics. "These young specialists work only part-time in rehabilitation; on the side, they push on with their studies and there comes a point when they want to leave us and go on to their professional work. This creates frequent turnover, and requires planning and active promotion of our kind of work inside technical education and vocational training institutions."

A considerable number of fellowships were awarded by UNDP for instructor training. The project was able to draw on the experience of other Latin American countries with a well-established capacity in specialised fields such as speech therapy and prostheses (Argentina) or statistics (Mexico). It also was encouraged by the success of a similar project in Colombia, which was run with ILO help from 1966 to 1974 and has since given hundreds of disabled people new hope and dignity as workers.

#### SHELTERED WORKSHOPS

After the Quito centre was created, similar centres were opened in two other cities: Cuenca and the seaport of Guayaquil. Among them, they have now a capacity for about 250 trainees.

Many of them have found their way into industry, thanks to a special placement unit created at the Labour Ministry. "The unit co-operated with us in following up on the ex-trainees whom we helped to find skilled job", says Mr. Cereda. "We could see that the employers were fully satisfied with the quality of their output and their sense of responsibility. It is a source of satisfaction to say that most of our deaf, blind or half-paralysed trainees now have stable jobs."

For the severely disabled, the government is creating a string of 'sheltered workshops'. One of them, opened in 1979 in Cuenca, employs disabled workers to assemble gas pipes under a sub-contract to a local kitchen manufacturer. These workers are paid the minimum salary.

"Development is gaining speed each day in Ecuador", says the ILO's regional adviser on vocational rehabilitation for Latin America, Antonio Lacal Zuco. "Capital investment, the growing number of iron and steel-works, the oil industry, the pace of road construction and of agricultural and agro-industrial development—all are potential sources of more disablement. It is very likely that the annual number of new disabled the country had in 1974 will multiply by three in 1983.

"At the same time, medical and surgical progress is such that many people who used to die or lose their entire working capacity because of diseases or accidents not only survive but can be trained to work again."



The work of the three existing centres will continue and the ILO has suggested creating additional facilities, particularly in outlying areas. The response of employers—most trainees placed by the centre are now drawing normal salaries as skilled workers—shows that rehabilitation not only is socially desirable but can pay as well.

—From ILO

## Finland

The International Year of Disabled Persons (IYDP) which will be celebrated in 1981 under the patronage of the President of the Republic, will include among others the following events:

- Four regional projects concerned with services for the disabled
- Participation in the international photographic exhibition arranged by the UNESCO
- Publication of a special postage stamp for the year of disabled persons.

The activities of the IYDP are being organised in Finland by a committee set up by the Council of State. The members of the committee represent the state administration, the central municipal organisations as well as the organisations of disabled persons. The committee is divided into three sections under the following topics: participation, organisation, and information. In addition to this, the committee has an executive sub-committee for international questions and for the preparation of the proposals to be submitted to the committee.

The section of participation is concerned with the possibilities of and obstacles to the participation of disabled persons in community activities. It also deals with the physical, psychological, and legislative obstacles restricting the life of disabled persons. The section of organisation concentrates on studying the ability of social institutions such as the state, the municipalities, different enterprises, and organisations to render services for disabled persons. As for the section on information, its task is to make known the rights and problems of the disabled persons to the public at large. The section also informs the disabled of their rights and the services available. It also analyses problems encountered by the disabled in obtaining information. This section will also inform the public about the activities of the committee and the sections during IYDP.

### FOUR REGIONAL PROJECTS

During 1981, the Finnish committee and its section on organisation will



run, among other things, four regional projects concerned with the services available for the handicapped. Their aim is to study from the point of the disabled persons the problems connected with the activities of the various organisations and with the obstacles in obtaining services, and to make proposals for improvement.

- In the province of Pohjois-Karjala (North Karelia), the topic of the project is education and the school system in particular.
- In the province of Kuopio, the theme is work, employment services, and housing.
- In the province of Oulu, the project includes the social and health services.
- In the province of Uusimaa, a study will be made concerning the cultural, leisure time, and traffic services from the point of view of the handicapped persons.

Since many of the decisions concerning the everyday life of the disabled are made at the local level, the Finnish committee has suggested to all municipalities the establishment of regional or local committees. The first of these committees was established as early as in May 1980.

The disabled and their organisations are represented in the Finnish committee. This ensures an active participation of the Finnish organisations of disabled persons in the arrangements for the year. During 1980, the committee received information of the plans of different organisations for a celebration of the year. In addition, a one-day conference was arranged for the representatives of the committee and the organisations.

In March 1980, the Finnish committee organised a seminar at the Hanasaari cultural centre to prepare the theme year. About 60 disabled persons participated in the meeting. By this method, an opportunity was provided for the disabled persons to be consulted on questions concerning them. The seminar provided the committee valuable expert information to be used in its future work.

Several ministries and central administrative offices are represented in the Finnish committee of the IYDP. The aim of this arrangement is to ensure that during the theme year all ministries and central administrative offices will pay special attention within their competence to the question concerning disabled persons. The aim is to bring about legislative or other reforms having a favourable influence on the position of disabled persons even after the theme year.

Vocational rehabilitation programme of employment accident insurance is the first of its kind in Finland and it may be of interest to know about it in some detail here.

Insurance against occupational accidents is the oldest branch of Finnish social insurance. The first Act was passed as early as 1895 with new Acts



in 1917, 1925 and 1935. The present Employment Accident Insurance Act was passed in 1948 but it has since been amended numerous times. The Act covers all employed persons, from industrial workers to white-collar workers and civil servants. Self-employed persons are, however, not covered. The employer with the exception of the state government, is liable to insure his employees with a licensed insurance company. For state employees similar compensations are paid through the state accident office. It should be noted that accidents occurring while travelling to and from work are covered by this Act. Occupational diseases are covered by a special Act, the present being from the year 1968.

### COMPENSATION FOR THE INJURED

The main forms of compensation for the injured are the following:

(a) Medical care which includes both in- and out-patient care and the common forms of medical rehabilitation as well as the supply of prostheses and other personal appliances.

(b) Daily allowance, 60 per cent of the earnings for a single worker, and 80 per cent for a person with dependants.

(c) Annuity which is divided into two parts, a basic annuity as a compensation for the loss of faculty, and a supplementary annuity to compensate for the loss of income. Both these parts, the basic annuity plus the supplementary annuity, give the totally disabled persons, 60 per cent of the earnings for a single worker and up to 90 per cent for a person with dependants, depending upon the size of the family. The supplementary annuity can vary individually according to the real loss of income caused by the accident. Thus the outcome of rehabilitation (success or failure) can have an effect upon the amount of compensation. Previously also the supplementary benefit has in most instances been paid according to a general schedule but in recent years more effort has been made to make this benefit more realistic and flexible.

(d) There are some additional benefits, *e.g.*, an incapacity supplement.

Vocational rehabilitation is a form of statutory compensation, *i.e.*, an injured person is legally entitled to it. More detailed stipulations are given by a special Act, the Vocational Rehabilitation Act for Recipients of Accident Compensation, of December 20, 1963. The main provisions of this Act are the following:

The aim of vocational rehabilitation is to improve the working or functioning capacity or earning possibilities of the injured. Rehabilitation benefits are granted on the basis of need which does not mean a means-test. The need must arise as a result of a work accident or occupational disease.

Originally, only a person still receiving compensation was entitled to rehabilitation. Very soon it was discovered that in many cases, *e.g.*, allergic occupational dermatoses, if the worker stayed away from his former working





place, the illness was cured and thus compensation ended. However, as soon as he went back to work, the illness was reactivated. To avoid this, the Act was amended in 1968 to allow the possibility of vocational rehabilitation as a preventive measure also in cases where the compensation was ended but there was of risk a recurrence.

### THE RANGE OF REHABILITATION HELP

The forms of rehabilitation are as follows:

(a) Examinations to assess the need and possibilities of rehabilitation and to plan a rehabilitation programme, *e.g.*, in the form of practical work tests in centres called work-clinics.

(b) Medical rehabilitation: Most forms of medical rehabilitation have for a long time been included in medical care covered in the original text of the Employment Accident Insurance Act. Medical rehabilitation according to the Vocational Rehabilitation Act, is aimed at those special needs that did not come under the original text. Practical example: Training for a car-driving licence for a person with a severe mobility handicap.

(c) Vocational training and practical work training for an occupation by which the injured is assessed to earn his livelihood. There are no limits as to the range of occupations or length of the training and thus a great variety of training programmes is possible.

Basic education in primary or secondary schools does not come under the benefits provided by the Act because the injured persons are supposed to have completed their basic education before entering working life. On some occasions, however, especially for the most severe cases, basic education, *e.g.*, in secondary schools, has been granted as the preliminary phase of a vocational training programme. Even studies at universities and other institutions of higher education are possible in principle but due to the age, qualifications, etc., of the clientele this level of training is not very common.

Although the general target of rehabilitation is to reach the same occupational status and level of income as before the accident, this is not possible in practice for many cases. On the other hand, if the rehabilitee is able to attain a higher occupational level and income through a training programme that was deemed objectively necessary, this will be allowed.

(d) Loans and grants for the purchase of tools and raw materials and for establishing one's own business are also included in the Act.

The economic provisions included in the Act are as follows:

(a) The costs of an approved rehabilitation programme are paid without a means-test. The principle is that the insurance provides that which the injured person himself would be required to pay if the liability would be his. Thus in cases where the maintenance of a rehabilitation institution is totally or in part subsidised by the state government, the insurance provides only that which remains of the total costs. Many of the services are completely



free for everybody or available at a very modest cost.

(b) The daily allowance or annuity is paid in full, *i.e.*, according to a 100 per cent invalidity during the course of the rehabilitation measures. This is the main economic basis of the implementation of the rehabilitation programmes. As these benefits are not taxed up to 20,000 FIM per year, they are in most instances able to give the injured person the possibility of maintaining his former standard of living during rehabilitation.

(c) The costs of board and lodging are paid separately according to certain norms if the rehabilitee stays in a centre as an in-patient or if he must move from his domicile for rehabilitation.

The main emphasis of the Act is on vocational rehabilitation. Medical and educational aspects have some influence. However, 'social' rehabilitation in the specific sense of the word remains outside the scope of the Act except as a general aim of the whole programme.

Rehabilitation benefits, as already mentioned, are a statutory compensation. Therefore the claims are processed according to the same methods as compensations in general, *i.e.*, the insurance company or state accident office makes the decisions and, if the injured does not accept the decision, he may appeal to the insurance court.

*—Compiled from Official Sources, Helsinki*

## Indonesia

For decades, 4 million physically and mentally disabled people in Indonesia have been neglected. A man on crutches can be ignored and underrated by his community and may believe himself without hope.

Now an important experimental programme in Indonesia is beginning to change public attitudes towards the handicapped and is teaching many disabled to become confident and even self-supporting within six months.

The scheme has been developed by the International Labour Organisation and the United Nations Development Programme, in collaboration with the Indonesian Department of Social Affairs. The main concept is to help the disabled within their communities rather than in institutions.

The ILO project manager, Sam Niwa, says the programme hopes to reach thousands of disabled people in rural areas. "If properly motivated and trained for skills for which there is a market, the disabled can achieve and enjoy normal, productive and purposeful lives in their community", he says. It is hoped that similar schemes can eventually be introduced in other developing countries.



### CAMPAIGN IN RURAL AREAS

The centre of the programme is a national training course for training rehabilitation administrators, managers of rural centres, vocational instructors and technicians capable of producing orthopaedic and other appliances for the disabled.

Each trainer is expected to return to his own area, train at least 10 field workers in his community, mobilise local resources and build up opportunities and facilities so that the handicapped can be socially reintegrated.

This means taking directly into rural areas the campaign for helping the handicapped, rather than dealing with them in urban institutions. For 30 years these institutions have fallen short of meeting the requirements.

"Even the new programme cannot proceed so quickly as to benefit all the present generation of disabled", says Mr. Niwa. "But we do aim to provide a service that will be sufficient to take care of all the new disabled cases that develop each year."

Four pilot schemes have already been set up which will serve as models for similar programmes being developed throughout the country. These are in East Java, South Sumatra and on the islands of Sulawesi and Bali. Four United Nations volunteers have been assigned in each area to help set up community based services and to devise programmes that can be most productive.

### EAST JAVA PROJECT

The East Java project, for example, is at Prolonggo, a small coastal town 100 kms. east of Surabaya. A base rehabilitation centre has been built and is already training disabled in sewing, radio repair, hair-cutting and making 'tempe'—local cakes made of fermented soyabeans.

At present 10 disabled people, including deaf and orthopaedically handicapped, are attending daily courses supervised by four trainers. Most of the disabled come to the centre by rickshaw-type tricycles from outlying villages.

"Our preliminary findings at these centres show that the disabled person sometimes has difficulty in believing that he can be rehabilitated and become a useful member of the community", says Mr. Niwa.

"On the other hand, his community often does not understand that anyone using crutches or using calipers is still able to play his part in the community.

"Sometimes well-meaning, but misguided people, give too much help to the disabled, taking away their feeling of self-reliance and restricting them to complete dependency on others."

Mr. Niwa says the scheme had been taken into the countryside because Indonesia is still predominantly agricultural and relies to a great extent on



subsistence farming. The majority of the disabled must be resettled in their home environments. Many of them have access to land and therefore heavy emphasis is laid on programmes which allow the disabled to get subsistence from the land and some sort of cash return.

"Communities sometimes have resources that have been neglected, inadequately developed or simply not recognised". Mr. Niwa says, "If they can be tapped and marketed, opportunities for providing livelihoods for the disabled may occur."

In each community, volunteers first have to seek financial resources and cooperation of local volunteers and organisations. This is where the UN volunteers with their special skills and professional qualifications inspire local people to devote time, money and personal effort to helping the handicapped, where previously the disabled were ignored and often lacked the basic necessities of life.

The ILO pilot programme in Indonesia is based on the principles of the International Year of Disabled Persons— "full participation and equality". The programme does not claim privileges for the disabled. Rather it seeks to provide for their economic and social recovery and have them considered as equals rather than as second-class citizens.

—From ILO

## Italy

The problem of the handicapped in Italy started to assume importance from the beginning of the 1960s and began to be approached from the social and cultural points of view, and not only from the medical point of view. Until that time the handicapped persons were considered, both by the national legislation and by the cultural milieu, from a medical point of view only. Every intervention in favour of the handicapped was oriented towards his medical treatment and very often the person was institutionalised.

In the decade 1970-1980, the old-fashioned concepts were turned up-side down and a serious attempt made at studying in depth the situation of the handicapped and at solving the problem in different other ways, taking into account the social needs of the disabled person. This meant that Italy was at the start of a period characterised by efforts of a practical nature and by the implementation of new laws, but Italy has not yet arrived at the evaluation of the results obtained and its eventual need for rectification. In other words, we are still at a transitional period.

The definition of the handicapped person in Italian legislation is the result of an evolution, thus reflecting the cultural changes. We have in fact laws from before 1970 that speak of the handicapped in medical terms and



classifying them clinically.

The national law 118 of 1971 starts speaking in general terms of the disabled, as a person that presents working and social problems. Regional laws in recent years define the handicapped person as an individual who, on account of particular circumstances, has suffered a reduction of his physical, psychological or sensorial capacities such as to make him liable to margination.\*

From these definitions of handicapped persons it is easy to understand how difficult it is to attempt at giving any precise data on the number, type and distribution of the handicapped in Italy. Furthermore, the little statistics available do not take into account the negative social factors existing behind the clinical classifications. However, it can be said that there is an average of 3 per cent to 7 per cent cases of new-born with grave psycho-neuro-muscular dysfunctions.

The rate of the seriously and less seriously handicapped referring to specific ages tends to increase from birth to the scholastic age (6 years), reaching at that age an average of 1 per cent.

#### NATIONAL LAWS

The first national laws that have approached the problem of the handicapped in a comprehensive manner are the law: 118 of 1971 concerning the general provision for the civil mutilated and disabled persons and the law: 482 of 1968 concerning a general policy on the obligation to employ the handicapped persons.

These two laws, although with many defects and defaults, have opened a new horizon for the social integration of the disabled. The law 118 in particular has its most salient points in the articles that concern the disabled persons' rights to be employed; the right of the disabled children to be integrated into the school system during the compulsory school years, with subsidised assistance for the seriously handicapped (that is, transportation assistance during school hours); the right to attend high school and universities; and access to institutions and special attention for the very serious cases.

Furthermore, that law tackles the problem of abolishing architectural barriers in schools, public offices, and public transportation and gives preference to the handicapped when assigning popular housing so that they may have the flats on the ground floor.

\*Example of regional law of Lazio N. 62 197 Art. 2: "In the present law it is understood as handicapped the person who on account of circumstances of traumatic nature occurred before, during or after birth presents a reduction of capacities physical, psychological or muscular or sensorial making him/her liable to be marginated".



This law contemplates also a vast series of interventions of assistance such as:

- monthly allowance for the disabled waiting to be employed.
- fixed pensions and monthly financial contributions for grave cases that require continued treatment.
- free medical assistance and, in particular, availability of prosthesis and various kinds of assistance and interventions at rehabilitation and physiotherapy.

The law 482 of 1968 concerns itself in a more specific manner with the integration of the disabled to working life. It protects 10 categories of disadvantaged persons (orphans, refugees), and amongst them the handicapped, establishing their right to be employed by public and private firms.

A salient aspect of this law is the equalisation of the handicapped with the rest of the workers from an economic point of view. According to this law the firms with more than 35 employees should hire disadvantaged persons. The law establishes that the disadvantaged persons' employment rate should be 15 per cent. This 15 per cent covers all the 10 categories of disadvantaged persons protected by the law. Out of this 15 per cent of disadvantaged persons employed, 15 per cent should be within the category of the handicapped. However, although the goal of the law is acceptable, the real number of the handicapped persons that are employed is small. There are sanctions against the firms that do not abide by the law, although in actual terms they are hardly applied.

Also at a national level there is another law which is very interesting. This is the law: 517 of 1957. This law abolishes the 'differential classes' in the schools. These classes were there in the old school system and received handicapped children with serious problems. These children were attended to by a specialised staff with special pedagogical methods. This meant a total isolation of the handicapped child from the rest of the children and an accentuation of their 'differentness'.

The new law abolishing the 'differential classes' ensures the integration of the handicapped within the normal classes thus improving the integration of the child into the scholastic and social milieu.

The reform movement and the revision of the problems of the handicapped have received an impulse from the constitutional reform during the years 1970-75 and this has facilitated the decentralisation of authority from the state to the 20 regions of the Italian republic.

#### DECENTRALISATION OF AUTHORITY

In this way many regions have been able to conduct in an autonomous manner their campaign for the integration of the handicapped into their



social context, thanks to the reduction of the political and bureaucratic problems resulting from the decentralisation of authority and responsibility. However, this has also brought about inequalities, as there are regions which are less well off economically and culturally and have frozen over the old fashioned concepts; on account of the medical and cultural backwardness, these regions resent the problems presented by the handicapped persons. The other and better off regions have completed and improved the laws of the government.

Among the advanced regions we have: Lazio, Lombardia, Liguria, Veneto, Emilia Romagna, etc., which, with their own laws, have created special services for the handicapped furnishing, on the one hand, all the necessary medical services and, on the other, providing programmes of support in order to favour their social integration.

These laws give an operational sense to the movement providing home assistance for the grave cases; lodging facilities; leisure time programmes; professionally trained staff that assist the handicapped child in his integration to the school and the adult in the working milieu and seek working opportunities for them; financial contributions for the working cooperatives; and summer camps for the integration of the handicapped, with the assistance of trained staff.

All these initiatives have brought to life specified programmes of which some examples are:

There is in Liguria. (north Italy) a very well framed working programme by which a relative number of handicapped persons have been integrated into a firm: they were first paid by a contribution made by the provincial administration and once their trial period was over the handicapped persons were accepted and paid by the firm itself.

In the region of Emilia (centre of Italy) a service has been organised by a group of communes whereby the handicapped children were taken to and fro school and integrated in the school joining the 'so called normal children'. not only in the school but also in a series of after-school activities so as to favour the total integration of the handicapped child into society.

These are only some examples and it may not be necessary to analyse all the programmes of all the regions, while it might be useful to analyse some volunteer initiatives.

Very significant are the several cooperatives of agricultural and artisan work that have arisen all over Italy with the participation of both normal and handicapped persons.

In the region of Lazio there is a community called 'Capo D'Arco' which has its headquarters in Rome and other offices in other parts of the province. In these communities mentally handicapped persons, the physically disabled, and normal persons work together. They do handicrafts and agricultural work. These communities are run autonomously and are self financed, offering also a training for those who intend to create a similar centre.





Another example of this is the Community of Lamezia Terme, a small city in Calabria, where 20 persons, some of them handicapped, have created a laboratory for printing paper, after having followed a training course in Capo D'Arco.

There is another community of this type in Como, the industrial area of north Italy. This community is called la Casaccia, where the people, some of them handicapped, carry out activities that are financed and maintained by the commune.

Another example of volunteer activity is that which devotes itself, together with the handicapped, to the campaign for the defence as the rights of the disabled. One of the most clear examples of this is the group that has founded the publication 'The Others' in Geneva (north Italy). This is a publication of the avantgarde addressed to all persons living on the margin of the society and maintained by a group of volunteers.

As it concerns the specific problems of the handicapped, the publication has conducted (together with the 'Law for the Right to Work') a political campaign, gathering the necessary 100,000 signatures in order to propose to the Parliament a new law on the right to work of the handicapped, which will mean an improvement of the already existing law 482 described earlier.

From among the group of volunteers of the publication 'The Others' a commission was created to overcome the architectural barriers. This commission has succeeded in obtaining remarkable improvement in the building construction and in the public places in favour of the disabled persons.

A movement for the liberation of the handicapped has risen in Lombardia, north Italy. It has favoured the integration of the handicapped in the schools, summer colonies, and of those at work.

Many other smaller groups act on a volunteer basis in small cities. They are financed by the regional administration. These groups have created several social centres for leisure activities, with facilities for participation by any kind of handicapped person, regardless of the kind of disability, mental or psychological.

### PROSPECTS OF IMPLEMENTATION

What emerges from this brief exposition concerning the situation in Italy are the prospects of full implementation of the laws that have come into force. These laws in fact are theoretically valid and capable of encouraging the integration of the handicapped. The main problem now is that of making sure that the laws are enforced and not disregarded by the public institutions responsible of their implementation.

It is difficult to evaluate the positive results of what has been done up to now. It is known, however, that there still exists 1,812 specialised institutes for the handicapped, although theoretically they have been abolished; and



that the integration of the handicapped in the working milieu is still the exception rather than the norm. It can be stated though, that, in every school, there are handicapped children that are attending the classes regularly and the experiences realised in the working milieu have been very positive both for the handicapped and for the normal children.

Concluding, all the legislative initiatives have yielded excellent results where there has been collaboration and acceptance on the part of the community (social groups, companies, schools, neighbours), while they have been frozen where they have met with resistance from the so-called 'normal citizens' who have obstructed the integration of the handicapped in their environment.

Therefore we believe that besides continuing the campaign and the effort for the improvement and the full implementation of the existing laws, it is necessary to insist on a cultural and educational movement so that the acceptance of the disabled persons will gradually become a normal feature of our culture.

—Anna Libri, Social Worker, Rome

## Japan

According to a survey in 1970, the total number of the physically disabled in Japan is 1.43 million. When the number of the disabled is compared to the total population of Japan, at the time of the survey, it is seen that 3.7 per cent disabled children below 18 years and 17.9 per cent disabled persons over 18 years exist in every 1000 population.

When the disabilities are classified in terms of cause, congenital abnormalities among disabled children amount to as high as 40 per cent, infectious diseases 12.2 per cent and other diseases 29.3 per cent of the total. On the other hand, among the adults, 56.3 per cent of the disabilities are due to disease and 26.6 per cent are due to accidents. In either case, disability resulted after birth, and 8.6 per cent are due to congenital abnormalities.

Compared to the work status of the general population, the status of the disabled workers in Japan is quite low; the number of the self-employed disabled composes 41.8 per cent of the disabled, while in the general population, it is 19.2 per cent and number of permanent employees consists of only 38 per cent of the disabled, while the general population shows 59.6 per cent.

### WELFARE SERVICES

Japan is carrying out various kinds of welfare services suited to the type



and degree for disabled persons. These services include medical examination, rehabilitation counselling, medical care, referral to an institution through the provision of the welfare personnel, etc. The welfare measures include: (a) welfare for physically disabled adults, (b) welfare for physically disabled children, and (c) welfare for mentally retarded persons.

In order to improve the technique for rehabilitation of the physically disabled, the national rehabilitation centre for the disabled was established in 1979. This is expected to act as a national organ to perform research and development of rehabilitation techniques, to give technical guidance on rehabilitation, to collect and distribute information, and to provide comprehensive rehabilitation programme extending from the medical aspect to the vocational one.

The Ministry of Health and Welfare is the supreme administrative authority for the administration of welfare for the physically disabled persons. The Ministry supervises the work of the heads of the local public bodies and makes decisions on the establishment and management of the advisory council on welfare for the physically disabled persons, the establishment of various standards, the designation of medical organisations to be in charge of medical rehabilitation, full or partial payment of expenses, and complaints which are registered.

Welfare services for the disabled children are provided under the child welfare law. These welfare measures include both the medical as well as welfare aspects such as prevention, early detection and treatment and long-term institutionalisation. Among the causes of children's disabilities, cerebral palsy is the greatest in number. Recently the number of children with disability due to accidents is increasing, especially accidents from automobiles.

The welfare measures for the mentally retarded place the emphasis on prevention, early detection, and early treatment. The government provides subsidies; the municipal bodies for day-care centres for mentally retarded children and also support educational camping programmes of voluntary organisations. Home helpers are available to families with severely mentally or physically disabled children or adults. Since 1978, severely retarded persons who stay at home have been visited by doctors and health nurses for medical evaluation and guidance. There is an insurance system where guardians of disabled children contribute varying sums and after their death the children are able to get substantial benefits on a monthly basis. Orphaned and abused retarded children are encouraged to be institutionalised and they get protection, education, and vocational rehabilitation. In 1979, there were 350 homes for mentally retarded children to accommodate over 26,000 retarded children in total.



## SPECIAL EDUCATION

Japan offers special education for handicapped children in two distinct forms: (a) in special schools, and (b) in special classes within ordinary elementary and lower secondary schools.

The former is for those whose handicaps are relatively severe in degree and the latter are for those whose handicaps are relatively mild in degree. Special schools exist for 5 categories of the handicapped: the blind, the deaf, the mentally retarded, the crippled, and health impaired. Special schools exist for seven categories of the handicapped: the partially sighted, the hard of hearing, the mentally retarded, the crippled, the health impaired, the speech discorded and the emotionally disturbed.

Teaching in braille is adopted in the schools for the blind and the oral method as well as auditory training are used in schools for the deaf. Education of the mentally retarded, the crippled, and the health impaired is still new, as the system of schools for the handicapped was instituted in Japan only as recently as 1947.

The primary problem facing special education since World War II has been the building of schools for the handicapped. The national government has taken the initiative by providing necessary financial assistance, resulting in a marked growth in the construction of such schools in recent years. Meanwhile, teacher-training courses in special education have been provided throughout the national education universities and in-service training courses for teachers have been undertaken in each prefecture.

There is an effective vocational rehabilitation programme in Japan which involves both the handicapped themselves and the employers of the handicapped. The main points of the programme are: (a) the quota system for employing the handicapped, (b) subsidies for the employment of the physically handicapped, (c) selective placement, (d) on-the-job training, (e) bonus to promote employment of the handicapped, (f) loans to help the handicapped commuters to purchase vehicles, (g) loans to help the handicapped to purchase Japanese typewriters, etc.

Attention is also given to matters like architecture and structure so as to help the handicapped, secure houses and parking places for them and to promote the environment conducive to work by the handicapped.

The employment of the handicapped has improved considerably with the cooperation of the employers, but the employment of the severely handicapped and mentally retarded has not been promoted as much as expected mainly due to the difficulty in assessing the vocational ability and the possible difficulties of management for the employers.

—Summarised from *'Rehabilitation Services for the Disabled in Japan'*, (1980), *The Japanese Society for Rehabilitation of the Disabled*, Tokyo.



## Kenya

There are no accurate statistics available on the incidence of disability in Kenya. According to international estimates, approximately 10 per cent of any population suffers physical, sensorial or mental impairment and requires special assistance if their ability to achieve maximum participation in the community is to be realised. In addition, the time, energy, funds and other resources of family members and others in the community are diverted in order to care or compensate for the limitations of disabled persons. International sources have concluded that at least 25 per cent of any community is thus affected by the existence of physical or mental impairments.

Sample surveys carried out by the division of vocational rehabilitation in 1973 and by the central bureau of statistics in 1977 revealed a disability rate of about 2 per cent. These surveys, however, were limited to the obvious disabilities such as blindness, loss of hearing, orthopaedic effects and mental retardation.

Physical, sensorial (limitations in vision, hearing or speech) and mental impairments are caused by many factors including genetic accidents, faulty pre-natal and post-natal procedures, dietary deficiencies, accidents, diseases and other causes.

The present estimates of disability incidence in Kenya are likely to increase in the future. As improved health measures produce a higher proportion of live births and prolong more lives, the disabled population will inevitably increase. Industrialisation, expanded use of motor transport, environmental pollution and other characteristics of the probable future are all likely to create more impairment. Without adequate attention to the related problems, more disability will result, which is costly both economically and socially.

While it is unlikely that a census of the disabled population in Kenya will reveal the true dimensions of the problem, nevertheless the information provided by a national survey, such as age and geographic distribution, can be most useful to the government in planning new health, educational, social and vocational resources for the disabled.

In Kenya, the Ministry of Health is stressing the importance of primary health care. Expectant mothers are cautioned against disease and malnutrition. Immunisation against notable diseases like polio and T.B. are now a widespread, accepted practice. Accidents on the roads, in industry and at home remain a worrying problem Kenya is yet to address itself to, while alcohol and drugs as disabling agents and the remedies thereof need increased attention. Of course, cognisance is taken of the fact that as in all other developing countries, poverty is discernible in most of the social and economic problems in Kenya also. Indeed, in Kenya, notwithstanding this fact, the government has long and clear policies concerning the main-



tenance of the welfare of the disabled. The Ministry of Health is actively working on prevention and intervention, the Ministry of Basic Education on providing special education facilities while the Ministry of Cultural and Social Services, in liaison with the Ministry of Labour, look after vocational rehabilitation and employment of the disabled. Substantial budgetary allocations are voted by Parliament for the disabled.

### VOCATIONAL REHABILITATION SERVICES

In Kenya, with a population of 15.5 million, those needing vocational rehabilitation may be 600,000 people. The aim of a vocational rehabilitation programme is to assist the disabled person in becoming a useful, producing member of the community and towards this objective the following services are provided:

#### *Assessment*

This is perhaps the most important aspect in the rehabilitation process since it will determine what specific measures are necessary to prepare the disabled person for employment.

#### *Vocational Guidance*

In the light of his physical, educational and vocational abilities as determined by tests of capacity and aptitude and the observations of the instructor and social workers, the vocational objective will be defined and the client will be advised accordingly.

In principle, counselling the handicapped and the non-handicapped is much similar but there is one important difference. Because of the limited opportunities open to the disabled, the counsellor has to be more specific in his advice, not guiding the client towards a family of occupations but towards a particular job or a specific type of employment and assisting him in securing that job. The vocational diagnosis and the means necessary to achieve the job objective is determined in cooperation with the client. It is essentially the client's decision.

#### *Physical Conditioning*

This is mainly achieved through the normal work and recreational processes in the vocational rehabilitation centre and can be assisted by the provision of remedial exercise sometimes with the use of special equipment.

#### *Social Services*

The social worker will assist the client in resolving problems with the home situation, family difficulties, financial matters and interpersonal relationships.



### *Skill Training*

Vocational training is necessary for most rehabilitees who require a skill to enable them to earn a satisfactory livelihood. Every effort is made to place the rehabilitee in a vocational rehabilitation centre within the close proximity of his home since it is desirable that he should be employed in his own community after completing training.

### *Selective Placement/Resettlement*

Job placement has been called the last link in the vocational rehabilitation process and it is the step by which the quality of all other services, whether medical, social or vocational, can be judged as factors of employability.

All training graduates from the rural vocational rehabilitation centres are provided with tool kits appropriate to their training and a quantity of raw material to enable them to establish themselves in self-employment.

Training graduates from the industrial rehabilitation centre in Nairobi are placed in wage employment with industrial and commercial concerns in both the public and private sectors. In the past, employers were reluctant to employ disabled workers but this attitude is now changing and job placement efforts are now meeting with much less resistance.

### *Follow-up*

The purpose of following-up the progress of former trainees is to determine if job placement has proved to be satisfactory and also to evaluate the efficacy of the vocational rehabilitation programme.

It also provides an opportunity to remove, as far as possible, any obstacles which may be hindering the disabled person from a satisfactory job performance.

The period of follow-up cannot be arbitrarily stated. Some clients will require a greater degree of after-care supervision than others but every effort is made to avoid dependence and stimulate self-reliance in the client.

### *Residential Accommodation*

Each vocational rehabilitation centre provides residential accommodation. A qualified housekeeper is employed to ensure that the domestic facilities measure up to a high standard of quality and that the physical and social well-being of the students is not neglected.

### *Training Allowances*

While in training each rehabilitee receives a monthly allowance which he can use to purchase any personal items he may require. He is encouraged to save part of the allowance.

### *Other Benefits of the Programme*

The purpose of rehabilitation training is not only to provide the disabled





person with an employable skill, but also to prepare him or her to enjoy the benefits and assume the full responsibilities of citizenship as a participating member of the community.

Training, therefore, is not confined to the vocational areas but includes literacy classes and lectures in citizenship, personal hygiene and civic responsibilities.

All students are encouraged to participate in sports activities which are organised at each vocational rehabilitation centre.

### VOLUNTARY ORGANISATIONS

Voluntary organisations have pioneered in providing services for the disabled in Kenya. They offer a variety of services, ranging from vocational rehabilitation to provision of special education and distribution of material aid for relief of those in distress. In recognition of their contribution, the government, through the division of vocational rehabilitation, allocates to them annual grants-in-aid. Some of the component voluntary organisations are: (a) Association for the Physically Disabled of Kenya; (b) The Kenya Society for Deaf Children; (c) The National League of the Disabled; (d) Kenya Sports Association for the Disabled; (e) Kenya Society for the Blind; (f) Jacaranda School for the Mentally Handicapped; (g) Salvation Army; (h) Cheshire Homes, Kenya; (i) Kenya National Council of Social Service; (j) National Christian Council of Kenya; and (k) Kenya Society for the Mentally Handicapped.

*—Official Publications made available  
from Kenya*

### Malaysia

"Broadly speaking, one in a thousand is born spastic. It can happen to anybody regardless of race and social strata." So Dr. Arthur Sandosham started his talks. He is the honorary director of the Spastic Children's Centre situated in Petaling Jaya, about 6 miles away from downtown Kuala Lumpur. He is better known as 'Dr. Sandy' among the children at the centre. The Spastic Children's Centre is maintained by the spastic children's association of Selangor which was established in 1960. The centre was started on a small scale with about half a dozen children, but it has now grown to a large centre catering for about 130 children. The Centre gives the children a combined service of education and therapy.

Then, what is a 'spastic'? "A 'spastic' is a person with cerebral palsy. This is a disorder of movement or posture which appears in the early years of life," Dr. Sandy explains. "It is due to damage or failure to develop normally in a small part of the brain controlling these activities."



According to his further explanation, cerebral palsy takes many forms and no two spastic people are alike. Some are so slightly affected that they have no obvious disability. Others may be clumsy in their walk or hand movements. In some serious cases, they find it hard to control their facial expressions and may seem to be feeble-minded or even mentally retarded. Cerebral palsy can be caused by many factors. It is not a disease. It may be caused by brain damage during pregnancy or delivery. However, in a number of cases the problem can be traced to an illness or brain injury during the early years of the child's life.

When a child is suspected to be spastic, he or she is brought to the medical clinic of the centre. At the clinic which is open every Monday these children are examined by doctors for a decision on whether they are really spastic or not. If found to be spastic, the children are admitted to the centre and a line of treatment is planned. Dr. Sandy emphasises the importance of bringing the children to the centre at an early age. "If children don't crawl, walk or talk at the age of 2 or 3, some parents take them to be slow learners and they leave them alone. In some cases, parents bring them at the age of 12 or 13, then the chances of improvement within the next few years are so little."

The services of the spastic children's centre comprise two categories, education and physical therapy. Children are referred to classes of different level according to their mental age and ability rather than chronological ages, ranging from nursery to primary school level. One of the main reasons that the chronological and mental ages of the children do not correspond is because few children start schooling at the age of six. This is due, among other reasons, to parent's lack of knowledge of the facilities available for spastic children.

At the nursery, which is run by two trained teachers, a relaxed environment with freedom of choice is provided so that the children can develop their own abilities. A variety of material is provided such as picture blocks, simple jig-saws, painting, block printing, etc. With the help of the teachers children learn to select activities they would like and gradually learn new activities. They learn through trial and error and repeat the activity. This repetition is a learning process and the more they repeat the more they learn and master the activity. Besides this, the environment provides the children with company so that they make friends, learn the correct use of materials. "The hours children spend here interacting with other children provides an excellent basis for social comparison and self-evaluation which has contributed greatly towards their mental development", Dr. Sandy points out.

#### THE SCHOOL SECTION

The school section at the spastic centre has a good number of pupils



attending the class five days a week. The syllabus and curriculum of work is the one approved by the Ministry of Education. However this is adapted to the individual pupil's needs taking into consideration the level of the child's understanding and ability. Since each child's handicap varies physically, mentally and socially, individual attention is given accordingly. Individual teaching methods are adapted to suit each child's needs. The children who are unable to write are provided with rubber stamps of a suitable size. Those with slightly better coordination are recommended to do typing.

### USE OF HYDROTHERAPY

"We are trying to make them improve both physically and mentally to the maximum possible extent. This means that the teachers, therapists and social workers have to work as a team in order to get the maximum result from a child", Dr. Sandy stresses. Apart from regular school work, children go for treatment to various therapists, namely, physio, speech and occupational therapists. For reading and speech difficulties the child is referred to the speech therapist. For correct posture in class they go to physiotherapist. Social problems are dealt with by the social worker.

In the case of spastic children, physiotherapy is the study of normal physical development and the practical application of the knowledge in cases of abnormal physical development. The development from controlling movement of the head to walking independently is normally automatic. If this development is stopped or never started, it must be corrected through physiotherapy. "Treatment should be sought as soon as parents even suspect that their child is not developing as other children. In a great many cases, if treatment is begun on a child within the first year of life, his prospects are much better than the one kept at home without treatment until 6 years of age or more", Dr. Sandy urges the importance of getting treatment at an early age.

One of the most popular therapies among children is hydrotherapy. A voluntary worker or therapist gets into the heated water with the children so that their muscles be relaxed. Since the body weight is supported by water, children can make various movements and therapists encourage them to do many things which will improve their condition. They also have occupational therapy the idea of which is to introduce the element of motivation, make them want to do things instead of just mechanically moving their arms. For instance, a therapist puts something which the child can catch so that he can make the movements by himself. Furthermore, the ultimate aim of occupational therapy is to develop maximum independence in self-help skills or activities of daily living of the child.

When children reach maximum degree of improvement the centre gives them vocational training. "Taking their situation, handicapped condition, as it is, we see what sort of jobs they can do. We try to make them



independent to have some sense of self-respect by earning some money.” Dr. Sandy mentions this with a broad smile. The Malaysian Airlines has given them some jobs to clean their earphones used in the planes. Even if it is a small amount of money they feel they really have accomplished something.

Spastic children are very lonely in their homes because their siblings who are normal all go to school or go out to play. When they are infants they are not aware of their conditions and as they grow older they realise that they are handicapped. They are more or less isolated from other family members. In worse cases, they go round damaging property by accident and parents get upset and lock them at the backroom. As a result of this they look forward to coming to the centre because they can mingle with other friends in the same situation.

Winding up his talks, Dr. Sandy urges general public to realise that there are a number of spastic children in this world who are trying to improve their handicapped conditions. “We would like to arouse their social conscience because we, as an association for the spastic children, feel that these handicapped children in this country are not given as much help and care as in some advanced countries.” It is also important to stimulate the overall responses of the spastic children by providing suitable environment at home so that they catch up on the physical experiences and stimulation they have missed all the years.

—Jongkoo Jeoun, Associate Information Officer  
UNICEF, Bangkok.

## Nepal

There have always been disabled people in Nepal. However, until recently very little attention was given towards their needs due to superstition, ignorance and mass illiteracy. The most common attitude of the Nepalis is to regard it as divine punishment for wrong done by the disabled in their past lives; hence, both constitutionally and socially, there is little provision, even now, for their rehabilitation and care. Programmes for prevention and rehabilitation are further hindered by a lack of accurate information about the number, demography and social status of the disabled people. This is due to the inadequate definitions of disability and inefficient, out of date, surveys—the last full one being the national population census of 1971. Nevertheless, in the last few years much has been done to improve their status in Nepal.

In the Mulki Ain (the Nepali constitution) a disabled person is defined as someone who has a deformity of the ear, nose, or eye, and it does not



take into consideration deformities of the limbs, neck or brain. In the 1971 national population census the definition includes only those economically inactive people who reported the cause of their inactivity as 'physical disability'. Realising the limitations of these definitions a much wider one was used in the 1980 sample survey of disabled people carried out by the IYDP 1981 National Committee. It includes those who, by virtue of congenital disease, birth defects and injury are incapable of living an independent social life, or are incapable of engaging in gainful employment and acquiring normal education consistent with age or sex. This definition includes those who are mentally retarded, whether their handicaps are severe or moderate. Based on the same principles, in the forthcoming national census, a broad definition to collect valid and authentic data has already been included.

### CONSTITUTIONAL AND LEGAL PROVISIONS

One of the main reasons why the status of disabled persons in Nepal is so poor is the lack of adequate legal and constitutional provisions for them. In the Mulki Ain there are only three measures for the care and protection of disabled persons: (a) On the recommendation of the panchayats, the zonal commissioners (*anchaladhiss*) should provide housing, food and two pairs of clothing a year for those disabled without relatives. Under this, the responsibility for the disabled is transferred from central government to the local panchayats administration and *Guthi Sansthaan*\*. (b) In either business or legal transactions between a disabled person and an able bodied person it is required that the disabled person bring, as a witness, either a relative or guardian to prevent exploitation. (c) If, when a summons is placed on a disabled person, he is unable to attend due to ill-health, the court case may be deferred until such time as he be fit to appear. Instead of employing legislation as a potent medium for the social and economic rehabilitation of the disabled, these provisions show only that society has recognised, directly or indirectly, that some provisional care for the disabled is a social obligation.

In each of the five year plans over the past 24 years no national policy for the disabled as such has been formed. However, in the fourth plan provision was made for the 'special education' of disabled people. Also in the fifth plan, by an act of government, the social services national coordination council under the chairmanship of Her Majesty the Queen was set up with six subordinate committees, one of which is the handicapped services coordination committee. This committee is responsible for the consolidation, expansion and coordination of the activities for the welfare of the handicapped. Although as yet not a part of the government itself, these bodies do have strong governmental support. Nevertheless, it is absolutely essential

\*Government organisation to look after properties endowed to religious places.



to create the necessary provisions under national or sectoral policy to allow the disabled to participate in the national development process.

### DEMOGRAPHY

The only reliable statistics on the demography of the disabled in Nepal is those provided by the sample survey of disabled persons 1980. Although the scope of this study is limited, only 8,001 households were examined, due to the poor definitions used in previous studies. It is the only acceptable one.

According to the figures projected from this survey there are 30.03 disabled persons per thousand population in Nepal. Of these 62.63 per cent were found to be male and 37.37 per cent female. This large difference is due to the fact that women in Nepal are socially and occupationally less exposed to the risks of accidents and also that biologically they have a greater resistance to disease than males. As far as geographical variations are concerned it was found that there is a higher rate of disability in the hills than in the terai. This is due to a higher incidence of accident-caused disabilities in the hills due mainly to the much harder terrain.

As a result of poor health facilities and poor preventive measures in Nepal on the whole, there is a significantly higher incidence of disease caused disabilities than accident caused disabilities. This is borne out in the survey, where 59.08 per cent of handicaps are either auditory or visual (33.38 per cent and 25.70 per cent respectively). However, in developed countries most handicaps are of the limbs, head, neck or spine and are caused by road accidents or industrial machinery. Nepal having few roads and little heavy industry does not suffer from these problems to such an extent (34.46 per cent of the handicapped suffer from these disabilities). Only 6.46 per cent suffer from mental retardation.

There are two main organisations for the service of the disabled—the special education council (SEC) and the handicapped services coordination committee (HSCC). The SEC was set up in 1971 under the Ministry of Education in the fourth plan. The main objectives of this council are the improvement of general and vocational education, teacher training, providing educational materials and the development and expansion of special education. The HSCC was set up in 1977 under the Social Services National Coordination Council Act in the Fifth Plan. The objectives of this committee are the removal of the social and administrative barriers obstructing the education, treatment and rehabilitation of leprosy patients, the physically disabled, the deaf, and the blind. The government has instituted many centres for the rehabilitation of the disabled persons, frequently with the collaboration of non-government organisations. Brief accounts of the services of these centres are given on next page.





### SCHOOLS FOR THE BLIND

Laboratory School, unit for the blind: the laboratory school has been educating blind children since 1964. Currently it has 34 students, of whom 22 are boarders and 12 day pupils, 26 boys and 8 girls, and they undergo integrated education from class 1 to 10. Apart from general education, vocational training in bamboo work, woodwork, knitting, weaving, embroidery and doll making is also given to them. Food, lodging, education and transportation are all provided free of charge. It is financed by the SEC.

Blind School at Dharan: This school is situated in the eastern part of Nepal, and was established in 1977 on local initiative. It caters for 40 students from grades 1 to 5. It is run by a local committee with financial assistance from the SEC. At present some new buildings are being constructed to provide better facilities to a larger number of students in that area.

### SCHOOLS FOR THE DEAF

Bal Mandir Deaf School: This school was founded in 1966 and currently has 142 students. General education is given from class 1 to 10, and vocational training is also provided. The teachers are trained outside the country. The SEC finances the school and the management is through a committee under the HSCC.

The School for the Deaf at Bhairawa: This school was founded in 1976 and currently has 40 students educated up to class 7. The teachers have been trained at Bal Mandir. It is managed by a local committee with financial assistance from the SEC.

### NEPAL DISABLED AND BLIND ASSOCIATION (NDBA)

This organisation was founded in 1969 by the late Mr. Khagendra Bahadur Basnyat who was himself disabled, and it runs the Khagendra new life centre. Here 103 disabled persons of various ages receive general education upto class 7 and four years of vocational training. There are also general medical facilities. The international human assistance programme (IHAP) is working to improve the quality of education and to set up a medical rehabilitation unit. When the Ryder Chesire Home and the four SOS Family Homes, now under construction, are completed in the middle of this year, an additional 32 severely handicapped persons and 32 disabled children will be admitted to the centre. The NDBA has established a branch in the western part of Nepal and is also trying to open branches in other regions.





## NEPAL LEPROSY RELIEF ASSOCIATION

This was established in 1969 under the chairmanship of HRH Princess Shanti Singh. Its activities include the management of the Malunga leprosy asylum, the education and training of leprosy affected children and the improvement of the popular attitude towards leprosy. It also runs two hostels for the children of leprosy patients—the Karl Gerold Home, Pharping, and the Marwadi Sewa Sadan, Kathmandu, where a total of 110 boys and girls live free of charge. Primary education is given to the children of lepers at Khokhana leprosy asylum. It is financed by government grant, foreign assistance (Dieuse en Ueberse) and public contribution.

There are some other organisations which help disabled persons. The orthopaedic appliances centre, started in 1971, with help from Bread For The World, makes artificial limbs, corrective shoes, calipers, etc., and trains technicians for its own needs. The Nepal leprosy trust assists other related agencies in the treatment and rehabilitation of leprosy patients. The human and national development service (HANDS), a missionary organisation, helps the mentally retarded children in Kathmandu, Pokhara, and Bhairawa.

Although in Nepal the programmes for the disabled are obviously inadequate (only 500 receive institutional care) there is a growing awareness of their needs and the facilities for their rehabilitation are being enlarged as fast as finance permits.

## OBLIGATIONS OF INDUSTRIES

Unfortunately there is no obligation for industries to employ handicapped people as such. This is a sad state of affairs since, due to prejudice, even when a disabled person is qualified and able to work, it is unlikely that he will be engaged without legislative compulsion. However, as part of the IYDP national plan of action, legislation is being recommended to the government to create better job opportunities for disabled persons. It is hoped that this legislation will be approved in the present session of government. There is also a public awareness programme being launched at the moment with a view to the removal of prejudices obstructing the economic rehabilitation of the disabled persons. The IYDP committee has received a positive response and through persuasion some disabled persons are being employed. It would seem that there is an increasing willingness on the part of both public and private enterprise to employ the disabled, but as yet this remains more theoretical than factual.

Although the facilities for the disabled persons are as yet inadequate and their social status is low, it must be remembered that here in Nepal we have been trying to make up for centuries of neglect in a mere ten years. Obviously more time is needed to improve their position in society, as social attitudes and prejudices cannot be changed overnight. However, it is heartening to



note that there is an increasing desire to help the disabled constructively. Therefore it is vital that the government should provide the necessary foundations in legislation for their care and rehabilitation, and thus capitalise upon this enthusiasm. Hopefully, the IYDP will provide the necessary focus and incentive for the improved care and economic rehabilitation of handicapped people. Only time will tell.

—*Madhav Om Shrestha, Member Secretary,  
Nepal International Year of The Disabled  
Persons (1981) Committee, Kathmandu.*

## **The Philippines**

At least one in every ten children is born with or acquires a physical, mental or sensory impairment in the developing countries where most of the world's children live. Yet little or nothing is being done to prevent either the occurrence of impairment or its damaging consequences. To understand these realities one needs only to visit any of the villages of Asia, Africa, Latin America or the Middle East, or any of the slums surrounding the cities in those areas. There one learns that along every road and path, in every cluster of huts, there are children who are being denied the possibility of personal development because they suffer impairments and because they are not receiving the benefits of the knowledge and skill that exist.

There is a campaign being carried on in two small villages in the Philippines—an experiment to prevent and treat impairments in young children that may yet lead to a better life for the country's young population. Called 'reaching the unreached', the project revolves around the concept that it is not always desirable to work so hard to buy the disabled child a wheelchair tomorrow when you can invest some time today training him towards self-sufficiency.

### **CHILD WITH IMPAIRMENT**

In a country where a great portion of the rural population is still in the clutches of ignorance and poverty the disabled child often is trapped between over-protection and negligence. A child with impairments is usually regarded and treated as 'abnormal' by the family and the community, thus, he may grow up without truly 'growing', and may only become a bigger burden in his family.

Josefina almost became such a burden. This mongoloid child at the age of 10 months was virtually a wilting head of lettuce in the arms of her mother. And though her body showed nothing but bones beneath her skin,



she gave the impression she was boneless because she could not even hold her head up. Her eyes were lifeless and she would not respond to talk, smile or sound. The colourful, empty shampoo bottles her mother gave her as toys did not interest her either.

But what was doing Josefina untold harm was the feeling of guilt and shame her mother had. Believing that an impaired child was something of a curse, Josefina's mother shielded the infant from the public eye while accepting the burden as 'the will of God'. Resigned to taking care of an invalid child for as long as the child lived, yet having no one else to help her with the housekeeping, Josefina's mother then often cooked meals, scrubbed floors and washed dishes with one arm while holding the child in the other.

No efforts have been made to improve Josefina's condition until she started responding to a field worker's 'tickling', a very simple no-cost intervention technique involving the stimulation of the muscles. The child was rolled over, encouraged to stand up, tossed in the air as her reluctant mother watched, fearing the child's bones would break. Although slightly startled at first, Josefina later on responded very well to the exercises, and to her mother's surprise, she did not even mind it when the field worker began to gently knead her arms and legs.

Josefina's mother was told by the field worker that, if left inactive, muscles can waste away, resulting in permanent disability of the child. Thus, upon instructions from the field workers, the 'tickling' became a daily therapeutic ritual for mother and child.

Only four months since then, Josefina today has put on a considerable amount of flesh, runs about the house, is a walker with a string of brightly coloured beads she plays with, and is just as responsive as any normal child of her age.

"If I hadn't seen Josefina's improvement with my own eyes, I would not have believed she was the same child I had thought her mother would get stuck with the rest of her life", said a neighbour.

More encouraging is the mother's attitude towards her child these days. The hostility has been replaced by amiability towards the field workers and her neighbours, her shame and guilt, by justifiable pride in her daughter's progress.

Josefina's case would be a very good example which proved that proper care at the early stage of impairment could prevent a child from being disabled and furthermore remained handicapped for the rest of his life.

—Jongkoo Jeoun, Information Officer,  
UNICEF, Bangkok.



## South Korea

In certain countries in East Asia and Pacific region, there are strange myths being practised. For instance, in Korea, it is considered bad luck for a person to encounter the blind or the crippled, especially in the morning. Recently when I visited the Samyook children's rehabilitation centre located on the outskirts of Seoul, the capital city of South Korea, the head nurse Miss Lee Myong Sook said: "Last year at christmas party for children in the centre, a sixteen-year-old girl revealed her bitter memory which can never be erased. Everyday in the morning on her way to school, she came across a man in the neighbourhood, and his attitude towards her annoyed her very much. Every time he met her he spat on the street and tried to turn his face away from her." Miss Lee had the similar experience herself when taxi drivers refused to stop the car for the handicapped children. She sometimes walks the children to the main street where they can get taxis.

Lee Myong Sook joined the centre in 1974 upon graduating from a nursing school. Since then she has been the teacher, mother, sister and, of course, all weather nurse to the handicapped children admitted at the centre.

"The patient-nurse relationship at this centre is fundamentally different from that of other hospitals. They are all children who are admitted to the centre. Our main concern is that the handicapped condition of the body should not affect the healthy character-building or emotional balance of a child."

Since its establishment in June 1952, the Samyook children's rehabilitation centre has been developing rehabilitation programmes and extending its facilities for physically handicapped children. The centre has moved to the present 600 sq. meter-premises in 1971 and it provides total rehabilitation facilities equivalent to international standards. The centre has a non-profit hospital, special school and a vocational training centre which have been remarkably renovated to function more efficiently as a total rehabilitation institute. On the third floor of the hospital where Miss Lee works there are about 100 polio and spastic children whose handicapped stage have good prospects for recovery of maximum physical function. The overall rehabilitation requires more than a year in many cases and 70 per cent of children are from poor families.

"It is a big mistake, if you think these children cannot compete with normal ones at school". Miss Lee points out.

"You can easily think that they are not capable of anything productive and consequently never try to give them opportunities. Another mistake lies in the prejudice to take them as emotionally imbalanced children. But once you visit here you will be ashamed of your misconception of the children. They are so bright and active and are willing to do anything despite



their physical condition. So our mission is to provide them with all the possible opportunities to whatever they want", says Miss Lee.

#### WHERE THERE IS NO PREJUDICE

Miss Lee emphasises that the society should not try to over-protect them, instead it should accept them as ordinary young citizens. It is ideal that this should be practised at home and then be gradually extended to the neighbourhood, society, nation and the world. Over sympathetic attitude can lead them to become incapable persons.

"Some parents are apt to think that keeping the children at home is better solution rather than letting them go out and play with non-handicapped children. Out of sympathy and overprotection, parents don't give even a chance for handicapped children to share simple housework", Miss Lee says this from her experience. "There are so many parents who instruct their children not to mix with handicapped children. I think this kind of attitude should be changed."

For total rehabilitation, the centre's social workers motivate the children to participate in their rehabilitation programmes. The psycho-social department gives intensive attention to social training. Every year, the centre has rehabilitation camps through which the children can strengthen their adaptability to new environment.

It is the wish of Miss Lee that the children she is looking after at the centre will grow up to be citizens of a society where there is no prejudice or maltreatment.

"All children should be equally treated whether handicapped or non-handicapped. More attention should be paid as to how to provide them better facilities and opportunities."

Since she is from a provincial town, she goes to bus terminal occasionally to take bus back home to see her parents living there. "I was very happy to spot at the bus terminal a public telephone booth specially designed for the handicaps. I hope this mere initiative will lead to more concrete long-term plans for the betterment of the handicaps in Korea."

—Jongkoo Jeoun, Information Officer, UNICEF, Bangkok.

#### USSR

World statistics say that there are 450 million disabled people on the earth, including 42 million blind and 70 million deaf people. Eighty per cent of people suffering from various anomalies live in the developing countries. Figures showing the number of disabled children are very distressing.



The UN has declared 1981 as the International Year of the Disabled and great attention is paid to the work of rehabilitation.

The Institute of Defectology is one of the 13 research institutions of the USSR Academy of Pedagogical Sciences. The Institute is engaged in comprehensive—pedagogical, psychological and physiological—studies. Scientists consider as their main objective to maximally bring together the paths of the development of anomalous and healthy children. This means that their aim is to establish and improve a special system of education and training for handicapped children and that this system should be close to the general system.

In this country the education and training of anomalous children has acquired the character of state care immediately after the October revolution. At that time a single education system was established and the education of handicapped children became its component part. Handicapped children were divided into four categories: the deaf-and-dumb, mentally handicapped, blind, and cripples. The differentiated system developed for these four groups exists now, and we attach prime importance to it.

The science of defectology in USSR has two fundamental features. The first feature is the absence of 'blind-alley' educational establishments (this is typical of the entire Soviet educational system), and the second is the strict differentiation of education of anomalous children. Today, due to theoretical studies and practical work of many years, we can educate each mentally or physically handicapped child in conditions which favour to the utmost his or her training for life and subsequent integration in society of normal people.

### DEAF AND DUMB

The types of special educational establishments are varied—about 15 types exist. For instance, the former category of the deaf-and-dumb. Today we have four types of schools for them—for the deaf, for children with dull hearing, for those who became deaf in later childhood and for deaf adults. At schools for the deaf, children receive education during 12 years on the scope of eight forms of the ordinary general education at school. However, our institute is successfully completing the experiment of many years as a result of which it will be possible to switch over to a ten-year education period.

Such intensification of educating a deaf child will become possible due to the technique of shaping his speech—the so-called motivation of speech communication. The method is as follows: every action of man is motivated and to urge a child to do something one should make him interested in it. The tuition process at school and work outside the school are based on this principle. One of the techniques is the use of dactylogy—a finger alphabet which is a form of speech by words and not by gestures.



Such a complicated process as the mastering of pronunciation by a deaf child is facilitated by a special concentric method of reducing a system of phonemes. At first a child is taught how to pronounce easy phonemes, while complicated phonemes are replaced by simplified ones close in sounding. This is a temporary phenomenon: in the course of tuition the speech of a deaf child is differentiated and is brought closer to normal.

In the development of communication through speech a system of practical activity of the deaf who handle the objects which surround them has been created. A special subject for junior forms—the object-practical instruction—has been worked out. This is specific propaedeutics for instruction in all usual school disciplines and which is of particular importance, in labour training.

Over the past few years we have paid particular attention to the use of residual hearing which to some degree is possessed by every child. For this purpose use is made of technical facilities and sound-amplifying equipment—both collective and individual.

A combination of these and other achievements permits us to speak about the gradual introduction of complete secondary education within the framework of a children's school for the deaf. Today a 19-year-old man who has finished our school gets such education in specialised technical schools, vocational schools or young workers' evening secondary schools.

#### BLIND AND DEFECTIVE EYED CHILDREN

Now about children with disturbances of eyesight. Earlier all of them were called blind. Now they also have several types of schools: for absolutely blind children and for children with eyesight comprising up to 0.05 of normal vision (there are about 15 per cent of such schools in which complete secondary education is given for eleven years), schools for children with poor vision (up to 20 per cent of normal vision) and evening schools for blind children and children with poor eyesight.

The teaching of general education disciplines at these schools does not present particular difficulties, and the problems here are linked with spatial orientation. The whole work is directed mainly on the use of the sense of touch: writing by braille's relief-dot scripture, reading of texts written in this scripture by touch and the perception of educational aids by touch. This slows down the tuition process but yields good results. To conduct laboratory work, say, in physics or chemistry, auxiliary technical devices are made with the use of the photographic effect, for instance, the photophone device. By the character of its signal—the pitch and the frequency of sound—a blind pupil can judge the correctness or incorrectness of his or her actions. So far we do not practise only those types of laboratory work which are linked with the identification of the colour.

At schools for poorly seeing children, eyesight still remains the basic





channel of obtaining information. The poorness of vision is compensated for by such 'props' as individual lighting of the school desk, texts printed in the enlarged type, enlarged illustrations and close-circuit television classes.

### MENTALLY HANDICAPPED CHILDREN

Now a few words about schools for anomalous children, in the first place, for mentally handicapped children. In the course of eight years they study the curricula of three forms of ordinary general education schools, but practically the leavers of such schools get a much larger volume of knowledge than ordinary third-form boys and girls. The whole tuition process in studies of general education disciplines—the mother-tongue, mathematics, natural sciences, geography and history—is maximally brought closer to life. Almost half of time is given to labour training in occupations accessible to such children. Good adaptation pupils who have finished these schools start working in ordinary enterprises and if adaptation is inadequate, they start working in enterprises employing disabled persons, where work is a kind of ergotherapy for them.

We do our best to rightly choose the type of the school for a sick child. The selection is strict, and this is quite natural. The first year of tuition is considered diagnostical and if doubts appear in the correctness of the choice, the child can be transferred to another school.

I would like to mention the type of schools for pupils known in world pedagogical practice as children with border mental retardation. They suffer from alalia or aphasia (dumbness) or general underdevelopment of speech. The tuition period is eleven years, and eight-form education is given here. It is worth noting that the children whose speech is successfully corrected can be transferred from any form to the mass school.

Another type of a special school which so far is experimental is a school for children with retarded psychic development. As a result of minimum disturbances of the functioning of the central nervous system, asthenic conditions or serious infectious diseases, such children make chronically poor progress at ordinary schools and certainly lose interest in studies. A special school returns their confidence in themselves and rectifies the course of their lives.

The final category is schools for children with disturbances of the locomotor system, *i.e.*, congenital or acquired malformations, the consequences of poliomyelitis, etc. In such cases our teachers face serious problems in teaching general education disciplines and in labour training. The main thing here is to maximally individualise tuition.

The medical station plays a very important role in all special schools. It has not only a paediatrist on its staff as ordinary schools do, but also the otolaryngologist, the ophthalmologist, the neutropathologist, etc. The medical and educational activities are inseparable from a single process.



All special schools in the USSR are boarding schools. Education in our country has always been free, but the upkeep in a boarding school depended in some cases on the material status of a family. Since 1970 it has also become free: the state pays not only for textbooks and educational aids, but also finances clothes, meals and lodging of a child at a boarding school during the whole period of tuition.

—*Professor Yuri Kulagain, Deputy Director,  
Institute of Defectology.*



# **Surveys of the Handicapped—Indian States**

## **Chandigarh**

The following concessions are available to physically handicapped persons in the Union Territory of Chandigarh.

### **SCHOLARSHIPS TO PHYSICALLY HANDICAPPED STUDENTS**

The object of the scholarships is to assist the physically handicapped to secure such education (academic and technical) and professional training or even training on the shop floor of the industrial establishment as would enable them to earn a living and become useful members of the society.

### **FINANCIAL ASSISTANCE FOR PURCHASE OF PROSTHETIC AID/ FITTING OF ARTIFICIAL LIMBS**

The aim of this scheme is to provide financial assistance to the physically handicapped for purchase of such aids and special gadgets as are necessary to increase their mobility and capacity, to reduce their dependence on other family members for daily routine work and also to improve mobility and locomotion and to restore in them the feeling of self-confidence and self-respect.

### **JOB RESERVATION**

There is reservation in group 'C' and 'D' posts/services to the extent indicated below:

(i) Blind	1 per cent
(ii) Deaf	1 per cent
(iii) Orthopaedically Disabled	1 per cent

The physically handicapped persons are entitled to relaxation of the upper age limit upto 10 years for purpose of appointment of group 'C' and 'D' posts. On nomination by the employment exchange, physically handicapped persons should not be subjected to the usual medical examination on first appointment and the question should be decided on the basis of the reports of the medical board attached to the special employment exchange



for the physically handicapped. The posts suitable for each of the categories, *i.e.*, the blind, the deaf and the orthopaedically handicapped have been identified.

#### ROAD TAX EXEMPTION

The handicapped persons in Chandigarh are totally exempted from the payment of motor vehicle tax.

#### CONCESSIONAL SUPPLY OF PETROL/DIESEL

Each physically handicapped holder of a vehicle in respect of which road tax is exempted is reimbursed 50 per cent of the cost of fuel purchased for the vehicle used by him. Government employees are paid conveyance allowance if they don't avail the facility of subsidised petrol.

#### FREE TRAVEL CONCESSION

All blind persons are permitted to travel free of charges in Chandigarh Transport Undertaking buses.

#### RELAXATION OF AGE BY 10 YEARS FOR THE GRANT OF OLD AGE PENSION

In the case of disabled persons, relaxation in age may be permitted to the extent of 10 years than the prescribed limit.

#### RESERVATION IN DWELLING UNITS

The Chandigarh administration has provided 1 per cent reservation in favour of physically handicapped persons in allotment of the houses built by Chandigarh Housing Board.

There are three institutions in Chandigarh for the rehabilitation of the physically handicapped, *viz.*:

- (i) Government school for mentally retarded children;
- (ii) School for the blind run by the Society for the Care of the Blind;  
and
- (iii) Lions school for deaf and dumb children.

In these schools, apart from the basic educational knowledge, the physically handicapped children are imparted training in various trades like, canning, weaving, candle/chalk making, music, etc., for their rehabilitation.

—Finance-cum-Social Welfare Department  
Chandigarh Administration, Chandigarh.



## Goa, Daman and Diu

The handicapped and the disabled persons are indeed the weakest and the most vulnerable sections of society and it is therefore necessary to ensure their rehabilitation so as to enable them to lead a happy, purposeful and meaningful life. There is a felt need to create a general awareness of the problems faced by the handicapped persons and once such problems are properly defined, an integrated approach could be adopted to tackle the problems.

The administration of Goa, Daman and Diu has reserved 3 per cent of the vacancies (posts) in group C and D categories for physically handicapped persons. This has been done in pursuance of the direction from the Government of India. Besides, under the scheme for scholarships to disabled persons which is in the central sector, scholarships to blind, deaf and orthopaedically handicapped persons are awarded for general education commencing from standard IX onwards; the rate of scholarship varies from Rs. 40 to Rs. 100 per month depending on the type of disability and the type of education/training. The total number of beneficiaries during the last three years and the expenditure under this scheme are as follows:

<i>Year</i>	<i>No. of Beneficiaries</i>	<i>Expenditure</i>
1977-78	9	Rs. 1,500
1978-79	9	Rs. 4,020
1979-80	9	Rs. 3,000

Considering the magnitude of the problem, the efforts made for the welfare of the handicapped and disabled persons in this Union Territory are neither adequate nor do they cover the entire range of such persons.

The year 1981 has been designated as International Year of the Disabled Persons. A state level committee has been set up in this Territory to formulate a plan of action for disabled persons. This committee has organised a state level function to mark the commencement of the International Year. As a first step, a survey of disabled persons is being conducted in this Territory which will indicate the magnitude of the problem. This would also enable the administration to formulate schemes for the education, training, and rehabilitation of disabled persons. The setting up of a multi-disciplinary institute for disabled persons to provide education, training and rehabilitation services is under consideration. The package of service will also include preventive and curative measures.

—*Local Administration and Welfare Department, Government of Goa, Daman & Diu, Panaji.*



## Gujarat

In Gujarat, at the time of bifurcation from the bilingual Bombay state, there were 20 institutions for the disabled persons. The number now is 65. The present programmes for education, training and rehabilitation of the physically handicapped in the state are encouraging and provide the base for future development. The categorywise classification of the institutions is as under:

Category	Government	Voluntary	Total
Blind	3	19	22
Deaf and Dumb	3	19	22
Orthopaedically Handicapped	2	4	6
Mentally Retarded	2	13	15
Total	10	55	65

### CATEGORYWISE REVIEW (EDUCATION AND TRAINING)

#### *Blind*

In most of the blind schools, education upto S.S.C. is given; however, some of the schools provide education upto 7th standard. Vocational training is simultaneously given to blind students. Separate vocational training centres for the adult blind are also run which provide courses approved by the technical education department and the trainees appear for the examinations held by the technical education board. The training programme includes elementary carpentry, canning, handloom and powerloom weaving, book binding, coir work, light engineering, armature winding, general mechanics, lathe work, etc.

Training in music is imparted from *prathmic* to *shiksha visharad*, both vocal and instrumental. Two schools are specially recognised as secondary schools for the blind and two schools are functioning as technical schools for them. In order to create better employment opportunities for the blind and to provide jobs in open employment, both in the private and public sector, two multi-category workshops, at Ahmedabad and Jamnagar, are functioning and they provide training in the above trades. One training college for teachers for the blind was established and it continued till a sufficient number of teachers were trained. It was closed for some time and the demand has again come up to restart it to provide more trained teachers, looking to the increasing number of students in blind schools. It is proposed to start this training college in the current year. The blind have proved to be good physiotherapists and massagists, and their services are being



made available in different hospitals. In one existing blind school, training in physiotherapy is imparted so as to meet the demand for physiotherapists. To provide braille literature, one braille press has been started in Ahmedabad. There is one talking book library and a braille library which provide literature to blind persons. In one of the secondary schools, integrated education for the blind has been introduced. Similarly blind girls from one institution are being sent out to normal day schools. These blind schools are spread in different districts and they provide free education, with lodging and boarding facilities, for which the state is giving liberal grants-in-aid.

#### *Deaf and Dumb*

Out of the 22 deaf and dumb schools, 2 are day schools and the others are residential. The state has framed a special curriculum upto 10th standard (7th standard of normal schools) for the education of the deaf children; a course for vocational training has also been framed. Training is imparted in tailoring and embroidery, printing and binding, carpentry, drawing and commercial printing, photography, etc. Two audiology centres are attached to the schools at Rajkot and Bhavnagar, which provide diagnosis facilities. One more audiology centre is proposed. One adult training centre for the deaf provides vocational training while one training college trains teachers for the deaf and dumb schools. Two schools provide partial integrated education to deaf children. These schools are equipped with modern educational equipments.

#### *Orthopaedically Handicapped*

Out of the 6 institutions for the orthopaedically handicapped, two are sheltered workshops which provide vocational training; one is specialised for giving training to leprosy patients. The other two institutions are homes for crippled children run by the state government which provide residential facilities during pre- and post-operation period. During their stay in the institutions, the inmates are provided with educational facilities and training in some crafts as well as post-operational exercises in physiotherapy and occupational therapy. One voluntary institution provides educational facilities to children and vocational facilities to adult persons. This is recognised as the adult training centre for the orthopaedically handicapped persons.

In addition to these, the Indian Red Cross Society, Ahmedabad branch, runs an *apang sahay ashram* which has an artificial limb centre, a hostel for the working handicapped and a physiotherapy centre at Ahmedabad. Besides, rehabilitation centres are attached to the U.S. hospital, Ahmedabad, and S.S.G. hospital, Vadodara.

#### *Mentally Retarded*

Out of the 15 institutions for the mentally retarded in Gujarat, 10 are





day schools and 5 are residential institutions for the education and training of the mentally retarded children. The state runs one mental hygiene clinic at Ahmedabad which provides diagnosis, treatment, and playroom services. One more clinic will be started this year on a voluntary basis at Navsari by the Indian Red Cross Society on a grant-in-aid basis. The B.M. Institute at Ahmedabad provides diagnosis, treatment and rehabilitation services to both children and adults. This institution also runs a multi-category workshop for the mentally retarded, which provides training in printing and book binding, carpentry, steel fabrication, tailoring and embroidery and house-keeping, etc. The state runs two homes for the mentally retarded children at Vadodara and Rajkot. It is proposed to start separate girls' sections within these schools. One day-school for the mentally retarded girls provides training in crafts and house-keeping. A majority of these institutions are residential and provide free lodging and boarding facilities along with education and training. The total number of beneficiaries of these institutions were 1,105 blind, 1,720 deaf, 496 orthopaedically handicapped and 356 mentally retarded persons during 1979-80.

Most of the institutions have their own buildings constructed with the state and central assistance and equipped well with modern amenities and scientific instruments and teaching aids.

### INTEGRATED EDUCATION

As stated earlier, integrated education for the blind children has been introduced in *Vividh Laxi Vidyamandir*, Palanpur, where blind students take education from 1st standard upto XIIth standard with sighted students. The number of these blind students is about 60. Special resource teachers are also provided. Besides, one of the secondary schools in Ahmedabad, run by a public trust, has also introduced integrated education for blind girls where 17 blind girls are taking education from 8th standard to 10th standard with other sighted girls of the school.

Likewise, partial integrated education has also been introduced in one of the primary schools at Surat and Vadodara run by the two municipal corporations, where deaf children participate in activities like craft training, games, excursions, etc., with normal students of the school.

Efforts are being made to persuade the educational institutions to introduce this scheme for the physically handicapped children in their institutions. Recently, the Government of India has revised this scheme and it has been made applicable to schools in rural areas also. This scheme will now be implemented by the state's education department.

### GENERAL SERVICES

#### *Scholarships*

The state scholarships are for students upto VIII standard and the



Government of India scholarships are from IX standard onwards. Both are being sanctioned and disbursed by the department of social defence in this state. The number of scholarships and the amount sanctioned during the last two years are:

<i>Year</i>	<i>No. of students</i>	<i>Amount (Rs. lakhs)</i>
State		
1979-80	1,551	4.62
1980-81	2,406	7.16
1981-82	2,500	7.60
Government of India (proposed)		
1979-80	1,030	5.80
1980-81	1,152	6.90

It is proposed to cover all eligible students during IYDP.

#### *Prosthetic Aid*

Financial assistance for prosthetic aids and appliances for starting petty trades is being sanctioned to physically handicapped persons. It is proposed to revise the rate of financial assistance from Rs. 600 to Rs. 1,000 per case and the income slab from Rs. 6,000 to Rs. 9,000 per year in order to provide help to all needy persons. In 1980-81, 375 beneficiaries have been sanctioned financial help (Rs. 1.66 lakh) against 250 beneficiaries for the year 1979-80.

#### *The Role of Voluntary Agencies*

Voluntary agencies have played an important role in the development of services for the handicapped. The state has encouraged voluntary agencies by revising the grant-in-aid pattern in which 100 per cent grant is given towards the pay and allowances for the employees and Rs. 75 per inmate per month as diet charges and two-third of the other admissible expenditures. Voluntary institutions are being encouraged to develop and expand their activities by taking advantage of the Government of India scheme of central assistance for voluntary agencies for the physically handicapped. The Government of India has released grants of over Rs. 19 lakhs to 21 institutions serving the physically handicapped during 1980-81. The state government has also released grant to the voluntary institutions as under:

<i>Year</i>	<i>Amount (Rs. lakhs)</i>		
	<i>Plan</i>	<i>Non-Plan</i>	<i>Total</i>
1979-80	8.81	54.71	63.52
1980-81	16.00	56.00	72.00



### *Rehabilitation Programmes*

The state started one special employment exchange for the physically handicapped at Ahmedabad in 1962. Similar special employment exchanges have been started at Rajkot, Surat and Vadodara to provide handicapped persons open employment in private and public sectors. The government has also reserved 4 per cent of the class III and IV category of posts for the physically handicapped. The roster system has also been introduced since 1979-80. The relaxation in age limit is made upto 10 years.

With a view to give a momentum to the campaign of employing disabled persons and also to encourage disabled workers, the state has instituted a scheme of granting state awards to outstanding employers of the disabled and the most efficient disabled employees. The scheme of retention allowance to the educated unemployed physically handicapped persons has also been introduced. Similarly, the scheme of giving financial assistance for maintenance of Rs. 30 per month to the old and physically handicapped destitutes has also been introduced since 1978-79. The age limit is relaxed upto 45 years for the physically handicapped persons. The rate of financial assistance is raised to Rs. 45 a month from April, 1980. About 1,200 are getting this maintenance assistance. Three voluntary organisations have employment and placement programmes for the physically handicapped.

The Mill Owners' Association of Ahmedabad have agreed to employ three handicapped persons in each textile mill in Ahmedabad.

The scheme of giving conveyance allowance to handicapped government employees and handicapped employees of voluntary agencies, receiving 100 per cent grant on pay and allowance of their staff, has also been implemented from April last year. Under this scheme the physically handicapped employees are given 10 per cent conveyance allowance of their basic pay, limited to Rs. 50 per month. The state government has also made a provision to provide land for residential purposes for the construction of houses to blind persons having an income upto Rs. 5,000 per year and who have no residential accommodation of their own.

A quota of 3 per cent is also reserved for all categories of physically handicapped persons in the houses constructed by the Gujarat Housing Board.

One hundred per cent concession is given to the blind person and his escort in state transport services. This concession is from January this year.

### CELEBRATION OF IYDP

The state government has appointed a state level committee to consider and finalise the state plan of action for IYDP 1981 and to review its implementation from time to time under the chairmanship of the minister of state for social welfare. The state has formulated schemes and programmes within the approved plan ceiling for the welfare and rehabilitation of the



handicapped. The Department of Social Defence, which is primarily concerned with these programmes, has provided Rs. 70 lakhs for the welfare programmes of the physically handicapped during the Sixth Plan and Rs. 28 lakhs for 1981-82.

The annual budget, plan and non-plan, for the education and welfare of the handicapped is Rs. 84.44 lakhs for 1981-82 which may go up to Rs. 100 lakhs, and will be 15 per cent of the total budget of the social defence department.

With the demand for services for the physically handicapped increasing, the state is doing its best to provide all services for their education, training and rehabilitation within its limited resources.

*—Social Welfare and Tribal Development  
Department, Government of Gujarat,  
Gandhinagar.*

## **Jammu and Kashmir**

In line with the UN resolution, the Government of India have decided to celebrate 1981 as the International Year for Disabled Persons. In this year, it is proposed to extend to the grassroot level, a pattern of services for the handicapped persons so as to ensure that as many disabled persons as possible are benefited. Jammu & Kashmir State Government have decided to fall in line.

Accurate statistics about the number of disabled persons in the state are not available. It is proposed to undertake a detailed survey alongwith the 36th Round of the National Sample Survey commenced in July 1981. The purpose is to work out firm estimates of the disabled persons and also other operational details. However, according to a limited sample survey conducted by the Government of India, the number of disabled persons in the state is about 35,000 (blind—8,590; deaf—5,547; dumb—4,056, lame—6,383, crippled—7,098; and mentally affected—3,340).

At present, the following facilities are being provided to the disabled:

- (a) A special stipend of Rs. 10 to Rs. 20 per month per child is given to those of the students studying up to tenth class whose father/parent/warden/guardian is physically unfit to earn livelihood. During 1980-81, Rs. 80,000 were spent and during 1981-82 the actual expenditure is likely to exceed this figure.
- (b) A special assistance of Rs. 50 per child per month (Rs. 75 in case of two children of the same parents) is paid to those of the children, who are deaf or dumb or polio stricken or are suffering



from other disabilities like mental retardation, orthopaedic and congenital disabilities, subject to the condition that their family income from all sources does not exceed Rs. 350 per month (Rs. 400 in case of two children). So far 2,500 cases of this nature have been covered with a total financial implication of Rs. 10 lakhs per year. During 1981-82, Rs. 10 lakhs have been provided for the purpose. This includes Rs. 3 lakhs earmarked for conducting special features in connection with the observance of 1981 as International Year of Disabled Persons.

- (c) Prosthetic aid is sanctioned for fixation of artificial limbs both of upper extremity and lower extremity to such persons whose monthly income from all sources does not exceed Rs. 400. The expenditure on this account during the last two years has been of the order of Rs. 1.51 lakhs and Rs. 0.82 lakhs respectively and during the current year, Rs. 0.82 lakhs have been earmarked for the purpose. On an average, 100 such persons are benefited annually.
- (d) Special assistance by way of subsidised supply of petrol/diesel is being provided to the handicapped persons who own their vehicles.
- (e) Three per cent of the non-gazetted services of the government are reserved for the handicapped.
- (f) A blind home with a sanctioned strength of 25 inmates has been established by the government at Jammu where the inmates are given free boarding, lodging, clothing, educational and vocational training facilities. Besides, the government have also been encouraging voluntary organisations which are engaged in the welfare and rehabilitation of the handicapped persons. Rs. 1.40 lakhs have been sanctioned as grants in favour of five such voluntary organisations.

#### PROPOSALS FOR 1981—INTERNATIONAL YEAR FOR DISABLED PERSONS

The disabled persons fall under two broad groups—those who can be rehabilitated and those who cannot be. Therefore, the schemes envisaged for the benefit of disabled persons have also been classified on the basis of the status of the beneficiaries. The destitutes among the disabled persons are already covered under the old age pension scheme. Under the scheme, a destitute who is 60 years or more and whose monthly income does not exceed Rs. 100 is given a pension of Rs. 50 per month. However, in case of a person who is incapacitated to earn living due to blindness, leprosy, insanity, paralysis or loss of one or more limbs or is disabled due to any other ailment, the age restriction does not apply, provided the monthly income does not exceed Rs. 400.

The following are the areas in which action is contemplated or is



initiated for the rehabilitation of disabled persons who can be rehabilitated:

- (a) Disabled persons in the age group of 12-40 to be given vocational training through trade oriented capsule courses. If it is not possible to start separate institutions for disabled persons, such short term courses can be introduced in the existing ITIs.
- (b) Funds to be earmarked for giving financial assistance for trained disabled persons towards carrying on self-employment ventures. Capital component in the tiny sector can also be subsidised and loans on easy terms for working capital can be provided.
- (c) Establishment of cooperatives by handicapped persons can be stimulated by providing special concessions. Industries department can help in the marketing of the produce of the handicapped entrepreneurs as well as voluntary organisations promoting such ventures.
- (d) In addition to the efforts of the ITIs in providing vocational training to the handicapped, there is a proposal for establishing a workshop for the handicapped persons.
- (e) It is proposed to involve the health department in increasing the health cover for children particularly in the field of immunisation and in taking up of the programmes of mental health for school children with a view of preventing emotional disturbances among them. The social welfare department proposes to give financial aid for preventive surgical measures because very often timely surgery can prevent permanent disability.
- (f) It has been suggested by the Government of India that a substantial number of young handicapped children should be brought to schools. The scheme referred to earlier is proposed to be modified so as to ensure that handicapped children in the age-group of 6-14 will be eligible for this assistance only if they are enrolled in a school. Exceptions, of course, can be there. The state government has a scheme for grant of scholarships to physically handicapped students. These efforts are aimed at bringing these handicapped children in the main stream by enrolling them in the normal schools rather than segregating them in separate institutions. These children will form the source from which persons for receiving vocational training at the later stage can be selected.

—Chief Secretary, Government of  
Jammu & Kashmir, Srinagar.



## Kerala

The various measures that have been taken up by the Kerala Government for the benefit of the disabled could be considered as a mainfest proof of the deep concern of the government in ameliorating the lot of the disabled. So also, in keeping with our traditions, various voluntary organisations in the state have come forward to supplement the governmental effort by organising and conducting a good number of programmes for the rehabilitation of the physically disabled. Thus in Kerala we have the example of a harmonious combination of both governmental and voluntary efforts in the rehabilitation of the disabled.

The government appointed Smt. L. Omanakunjamma, IAS (retired) as a commission to study the problems of the physically and mentally disabled in the state and to recommend remedial measures. The commission, after making an extensive study of the problems, has submitted its report. The recommendations of the commission are being implemented stage by stage.

### EXISTING SERVICES FOR THE DISABLED

There are at present 15 schools for the education of the blind and the deaf in Kerala. They include two departmental schools solely for the blind, one departmental school solely for the deaf, two departmental schools for the blind and the deaf, five schools under private management solely for the blind, four schools under private management solely for the deaf and one school under private management for the blind and the deaf. Educational facilities upto VIIth standard level are available in most of these schools. The children are given free boarding and tuition, subject to income ceiling.

Scholarship facilities are also available to the disabled for all stages of studies including academic and vocational at different rates. About 4,500 disabled students received scholarships for various courses during 1980-81.

Under the integrated education scheme, disabled children pursue their studies along with the normal children in the normal schools. Under this system, the totally blind and the partially sighted, the partially deaf, and the orthopaedically handicapped pursue their educational courses. They are also eligible for exemption from the payment of all kinds of fees. They get scholarships and other allowances.

### VOCATIONAL TRAINING FACILITIES

At present vocational training facilities exclusively for the disabled are available in nine institutions. They include two departmental and seven private institutions. These institutions provide training mainly in book binding, cutting and tailoring, leather works, plastic works, weaving,





printing, composing, proof reading, candle making, plastic moulding, coir-mat making, umbrella making, chalk making, etc.

The trainees are eligible for stipend from government.

There is one ITC and one JTS for the deaf. The former is under private management and the latter departmental. Similarly there is one institution for providing training to the blind in light engineering operations. The trainees are eligible for scholarships. In addition, 5 seats in each of the 12 JTSs have been reserved for the disabled.

The state government offers stipends to the disabled undergoing vocational training or inplant training in any recognised institute.

### EMPLOYMENT FACILITIES

There is a special employment exchange in Trivandrum for promoting placement of the disabled in suitable vacancies. The Kerala Federation of the Blind is also having placement service for the blind. This service is aided by the state government. The vocational rehabilitation centre, a Government of India institution, has facilities for the evaluation and placement of the disabled.

The P&T department has evolved a special programme to instal telephone booths at important centres manned by the disabled on a commission basis. A number of disabled persons find employment on this line.

Disabled persons are eligible for relaxation of the upper age limit prescribed for recruitment to public services. The orthopaedically disabled are eligible for relaxation of ten years and the blind and the deaf 15 years.

The physically disabled are eligible for the award of grace marks in interviews held by the state public service commission. Under this programme, the orthopaedically handicapped are eligible for upto 10 per cent marks and the blind and deaf upto 12 per cent marks at the discretion of the commission.

The state government has a scheme to give financial assistance to the disabled to cover their expenses in connection with their journeys undertaken to appear for interview with employers. In deserving cases escorts of the disabled also are eligible to get financial assistance under this scheme.

### RESERVATION OF VANCACIES FOR THE DISABLED

The state government have decided to reserve 3 per cent of the vacancies coming under class III and IV groups for the disabled, one per cent each for the blind, the deaf and the orthopaedically handicapped in government departments and corporations.

National awards for the outstanding employers of the physically handicapped and for the most efficient physically handicapped employee are available for the promotion of the employment of the disabled.

The state government is implementing a scheme for the promotion of



self-employment of the disabled. Under this scheme the physically disabled individuals get Rs. 500 each for starting small trade or business of their own. During 1980-81, 600 persons received aid under this scheme.

Disabled persons who do not have any means of support are given Rs. 55 per month as pension.

Blind persons are allowed free travel in KSRTC buses and departmental boats. The orthopaedically disabled with 50 per cent and above disability are eligible for concessional travel in KSRTC buses.

The state government has introduced a scheme to pay a special allowance of Rs. 50 as conveyance allowance to the blind and orthopaedically disabled government employee. Part-time and contingent employees are eligible for Rs. 25 each.

There are 8 departmental homes for the care and protection of the disabled. The inmates of these departmental institutions are given a monthly maintenance grant of Rs. 85 each. Under the scheme for giving grants-in-aid to orphanages there are well over 40 homes for the aged and infirm in receipt of monthly maintenance grant at the rate of Rs. 45 per inmate.

There are well over 14 institutions for the care and protection, training and education of the mentally retarded. Out of these, three are departmental institutions.

In addition, the state government has a scheme for payment of scholarships to the mentally retarded children studying in private institutions. Under this scheme Rs. 30,000 were spent during 1980-81.

#### ASSISTANCE TO VOLUNTARY ORGANISATIONS FOR THE DISABLED

Under the central scheme of assistance to voluntary organisations, the disabled institutions and organisations in Kerala get grants-in-aid on the recommendations of the state government for initiating and expanding programmes for the education, training and rehabilitation of the disabled. Seventeen projects from 12 organisations with a total expenditure of about Rs. 30 lakhs were recommended during 1980-81.

In addition, the state government has a scheme to give financial assistance to voluntary organisations for starting and expanding production or to industrial units for giving employment to the disabled.

There is a scheme under government consideration for sanctioning financial assistance for the purchase and supply of prosthetic and orthotic appliances to the disabled, including fitting.

There is a full-fledged department of physical medicine and rehabilitation in the medical college, Trivandrum. With the collaboration of the Artificial Limbs Manufacturing Corporation of India, a regional limb fitting centre has been established in the Trivandrum medical college with facilities for the fabrication of various types of prosthetic aids and appliances. A peripheral limb fitting centre is also functioning in the medical college,



Calicut. Disabled persons get special aid at concessional rates from these centres in addition to therapeutic services.

Government has set up a corporation for developing employment oriented programmes for the disabled. The corporation has at present a departmental store and a mobile sales unit. In addition, it is developing an artificial limb centre.

The corporation proposes to take up the following new schemes also:

1. One thousand sales cabins.
2. Placement of handicapped persons as apprentices.
3. Scheme for assistance to handicapped persons who have taste in radio assembling.
4. Scheme for assistance to book binding units.
5. Assistance to handicapped persons who know plastic work.
6. Scheme for organising tailoring units.

#### THOUSAND SALES UNITS

One thousand sales units are to be started during IYDP itself. The object of the scheme is to create employment opportunity for handicapped persons. The approximate cost of the scheme is Rs. 85 lakhs. Out of this Rs. 35 lakhs is set apart for working capital and this amount will be from institutional sources. One thousand sales cabins will be constructed covering all districts in Kerala. It is estimated that the cost of the sales cabins will be Rs. 50 lakhs. This amount will be collected from various agencies as donation/voluntary contribution. The district collectors are entrusted with the collection of voluntary contributions.

One thousand handicapped persons who are interested in conducting small shops will be selected and one cabin each will be allotted to them. The beneficiaries will have to get the working capital assistance through scheduled banks at their own instance. The State Bank of India has come forward to give this assistance.

#### NEW SCHEMES PROPOSED BY GOVERNMENT

The state government proposes to implement the following new schemes during the IYDP:

- Establishment of cooperative societies for the physically disabled with governmental share participation on the pattern of industrial cooperative societies for women. It is hoped to give employment to 2,500 physically disabled through these cooperative societies.
- Setting up an institute for research, education, training and rehabilitation of the mentally retarded. Necessary project report has already been prepared.



- Setting up of a rehabilitation centre for the benefit of mental patients discharged from mental hospitals.
- Improvement of the facilities in the existing institutions for the disabled.
- Establishment of five care homes for disabled children.
- Institution of state awards for outstanding employers of the physically disabled and for a most efficient physically disabled employee.
- Setting up of an ITI for the physically disabled.
- Enhancement of pension to the disabled from Rs. 55 to Rs. 75 per month.

Government have already issued orders to retain provisional disabled employees up to the end of 1981. Similarly, government have issued orders exempting vehicles owned by disabled persons from the payment of road tax so as to enable them to avail the benefit of petrol subsidy being allowed by Government of India.

The state government proposes to develop regional limb fitting centres with therapeutic facilities under the medical colleges of Kottayam, Alleppey and Calicut during the current financial year. A rehabilitation training centre is to be developed with assistance from World Health Organisation under the medical college, Trivandrum.

—*Local Administration and Social Welfare(M)*  
*Department, Government of Kerala, Trivandrum.*

## Madhya Pradesh

According to the latest census report, the total population of the state is 52.13 million. Out of this, children between 0 to 5 years comprise 40 per cent. A survey conducted by the state's department of social welfare in 1979 shows that the population of handicapped persons was 120,000, out of which 96,000 lived in rural areas and 24,000 in urban areas. Among the handicapped, categorywise population was, roughly, 35,000 blind, 13,000 deaf and 51,000 orthopaedically handicapped; the survey could not give a correct idea of mentally retarded persons.

The state-level committee for the welfare of the handicapped, which was constituted by the state government in the context of IYDP, considered the above figures inaccurate. In the committee's opinion, the population of the handicapped should be about 10 per cent of the total population. If this is accepted the handicapped population in the state should be about 500,000. With a view to arrive at a correct figure, a detailed survey is being conducted all over the state from May 1981 and its results are likely to be available by the end of the year. In addition to the number, this survey will also indicate the social and economic status of the handicapped and will give an idea of their individual needs.



#### ADMINISTRATIVE SET-UP FOR WELFARE OF THE HANDICAPPED

The subject 'welfare' of the handicapped is dealt with in the social welfare department at the state and at the directorate level and the director, panchayats and social welfare is in charge of this department. As stated earlier, the government has constituted a state-level committee under the chairmanship of the minister for social welfare. The secretaries of finance, health, education, industries, general administration, labour and social welfare departments are its members. Besides, there are nine representatives of voluntary organisations working in the field. This committee has been set up to advise the state government in matters related to the preventive, curative and rehabilitative aspects and the policy formulation for the welfare of the handicapped.

In the directorate of panchayats and social welfare, the welfare of the handicapped is dealt with by a deputy director who is in charge of correctional services also. There is an assistant director and some ministerial staff. At the divisional and district levels, there are no separate officers to deal with this subject, but the divisional deputy director of panchayats and social welfare deals with the welfare of the handicapped also and functions as a controlling officer of all the schemes running in his division. Similarly, at the district level, the district panchayats and welfare officer are in charge of all social welfare schemes also.

#### INSTITUTIONS FOR THE HANDICAPPED

Most of the institutions for the training of handicapped persons are run by the state government. Private institutions are very few. Government institutions are as under:

##### *Schools for Deaf and Mute*

Two schools for deaf and mute are run at Gwalior and Rewa. The schools have no hostel facilities. Classes are run in day time only. In the current financial year, hostels are proposed to be attached to these schools for which government sanction is awaited. Both the schools are primary-level schools, each with a capacity of 50 children. There is only one teacher in Rewa and 3 teachers in Gwalior. Both the schools are running in rented buildings.

##### *Residential Schools for Blind, Deaf and Mute*

Six such schools are run at Bhopal, Sagar, Jabalpur, Bilaspur, Raipur and Jagdalpur, all of which are divisional headquarters. Each institution has a different staffing pattern, depending upon the number of children admitted in the school and in the hostel. The teacher: student ratio roughly works out to 1:17. At Jabalpur the institution is in a government building specially designed and constructed for the purpose. Bhopal also has a government building, which is old and not adequate for the purpose. In the



other places, the schools are in rented buildings, hardly suitable for the purpose.

The school at Jabalpur is a higher secondary school recognised by the education department. The school at Bilaspur is a middle school and in the other places they are primary level schools.

The strength of the blind and the deaf-mute children in the above schools is: Bhopal 67; Sagar 32; Jabalpur 110; Bilaspur 120; Rewa 15; and Raipur 63.

#### *Integrated Education for the Blind*

At present this scheme runs in one school each at Gwalior, Indore, Raipur, Jabalpur, Bhopal and Bilaspur only. Under this scheme, blind children are admitted in normal schools to study along with sighted children, with the help of one resource-teacher at every place. The blind children often face difficulties in obtaining suitable readers and writers during the examination period and have to depend on assistance from the education department.

#### *Braille Book Transcribing Unit*

A cell has been established in the school at Bhopal for transcribing school books in braille script. The work is done by hand and therefore the output is very low and the cost of books goes very high. Effort is being made to obtain a braille duplicator from the National Association for the Blind, Bombay, on a rental basis. The Government of India has also been approached to put up or assist in putting up one braille press in Madhya Pradesh.

#### *Institutions for Orthopaedically Handicapped Children*

Three institutions are run at Indore, Raipur and Jagdalpur especially for the orthopaedically handicapped children. Those children who are in need of long term medical treatment are admitted in these institutions where they are given education and treatment simultaneously. The institution at Indore is of the level of a middle school and the rest are upto primary school standard. The institutions are headed by superintendents (class II) who are qualified in occupational therapy. These institutions are located in private rented buildings which are rather unsuitable and have no scope for extension.

The children, after completing education in schools, are either sent back to their parents or to these institutions run for adults for admission. There are no rehabilitation services in these institutions.

#### *Home for Mentally Retarded Children*

There is only one home in the whole state and is run by the government at Indore. It has a capacity for 50 children. Hostel facilities are available



for children coming from outside Indore. The home is headed by a superintendent, who has a post-graduate degree in psychology. He is assisted by an occupational therapist, teachers and craft instructors. The institution provides educational facilities upto VIII class. No rehabilitation services are provided. Children above 16 are either handed over to parents or sent to other institutions for adults for their further training and rehabilitation.

*State Home for Adult Deaf-Mute and Orthopaedically Handicapped Persons*

This is a residential institution at Indore with a capacity for 60 persons. It functions as a vocational training centre where training is imparted in book binding, composing and printing, carpentry and tailoring. It has hostel facilities to accommodate 15 handicapped persons. A superintendent is in charge. There is no separate placement or employment officer to help the trained persons in seeking jobs or in getting self-employment. The institution is in a government building, suitable for the purpose but has no space for expansion.

*State-level Institute for the Handicapped*

This state institute has been started recently at Jabalpur for the orthopaedically handicapped, deaf-mute and mentally retarded adults, for their treatment, training and rehabilitation. The institution has facilities for 100 handicapped persons and also provides artificial limbs to the handicapped. The handicapped persons are also sent for their vocational training outside the institution depending on their aptitude and nature and intensity of their disability. The institution is in charge of a superintendent, a senior class II officer, who is assisted by three instructors for carpentry, leather work and tailoring. In the current financial year, it is proposed to establish employment and placement services in the institution as a step of its development.

### SCHOLARSHIPS TO HANDICAPPED STUDENTS

Under the state scheme, scholarships are given to handicapped children studying in primary and middle schools. The rates prescribed per child are Rs. 25, Rs. 30 and Rs. 35 per month, respectively, for ten months. The scholarships are initially sanctioned by the divisional deputy directors and can then be renewed by the district panchayats and the welfare officer. In 1980-81, 500 students got the benefit of these scholarships.

Under the Government of India scholarship scheme, scholarships to students studying in higher secondary schools, colleges and training institutions are sanctioned by the director, but now it is proposed to empower the divisional deputy directors to sanction these scholarships also.

Under the state government scheme, financial assistance is granted to handicapped persons for purchase of artificial limbs. This assistance is restricted to those handicapped persons whose income is below Rs. 500





per month. The assistance covers the cost of artificial limbs only. The handicapped person himself is expected to bear the expenses for going to the artificial limb centre and to get the limb fitted. This deprives many poor and needy handicapped persons of this facility mainly because they are not in a position to bear the travel and fitting expenditure. In a few cases, voluntary organisations like Rotary/Lions Clubs come forward and finance such cases. The artificial limbs mainly include hand-driven tricycles, hearing-aids, calipers, crutches, artificial legs, special shoes, belts, wheel-chairs and glasses for the partially blind, etc. There are three artificial limb manufacturing centres run by the department of health and family welfare, Madhya Pradesh. These centres are attached to medical colleges at Indore, Bhopal and Jabalpur.

However, under the Government of India scheme sanctioned in IYDP, all the necessary expenses borne by the handicapped persons with a monthly income not exceeding Rs. 1,500 per month will be borne by the Government of India. This has come as a great boon. The scheme is being implemented in this state through the district rural development agencies and three voluntary non-official agencies.

Under the Ministry of Labour, Government of India, there is a vocational guidance and rehabilitation centre at Jabalpur. The centre provides facilities for vocational training, aptitude test, and employment to handicapped persons. The centre works in close coordination with the special employment exchange for the handicapped, Jabalpur, and voluntary and government institutions in the state. In 1980, 322 handicapped persons were rehabilitated through this centre.

Seventeen voluntary organisations are working in the state for the welfare of the handicapped. Out of these, 7 are at Indore, 3 in Gwalior, 4 in Bhopal and 1 each in Ujjain, Durg and Rewa. Two of them, namely, Gandhi Samaj Sewa Mandal, Bhopal, and M.P. Drishtihin Kalyan Sangh, Indore, are also running workshops for the handicapped, while the rest are running educational institutions only. Only one has the facility for placement and employment of the handicapped. The other districts (34) have no voluntary institutions for the handicapped.

Voluntary institutions receive grants-in-aid from the state government 70 per cent of their approved expenditure. In 1980-81, over Rs. 3 lakhs were sanctioned for the purpose. A decision has been taken in the context of IYDP under which 100 per cent of the expenditure incurred by voluntary institutions on the salary of teachers for the handicapped will be reimbursed by the state government.

#### NEW SCHEMES UNDERTAKEN BY GOVERNMENT IN IYDP

*Integrated Education for the Handicapped—Government of India Scheme*

The scheme is to be implemented in 27 selected schools in the state.



Action has already been taken for identifying the schools and teachers and the handicapped children in these areas. Arrangements for training of teachers are being made with the assistance of the Government of India. In the first phase, it is proposed to enrol the orthopaedically handicapped and blind children in these selected schools along with ordinary children and place a trained resource teacher in each school. In the second phase, deaf children will also be covered under the scheme and it will be implemented in more schools in the state.

#### *Sheltered Workshops*

Three sheltered workshops for the handicapped are proposed to be set up in the current financial year at Rewa, Dhar and Bilaspur. In the first phase, vocational training in tailoring, soap-making, typing and printing and composing is to be started in these workshops. Hostel facilities for handicapped men and women are also to be provided. The anticipated expenditure in the first year is Rs. 9 lakhs.

#### *Homes for Mentally-Retarded Children*

Two more homes for mentally retarded children (in addition to the one functioning at Indore) are proposed to be set up at Jabalpur and Raipur. These will be residential institutions providing education and vocational training for mentally retarded children.

#### *Buildings for More Institutions*

Proposals for providing hostel facilities in the deaf and mute schools in Rewa and Gwalior are also under consideration of the state government.

It is also proposed to take up construction of government buildings for the blind, deaf and mute school, Bilaspur, and for the deaf and mute school, Rewa.

#### *Vehicles for More Institutions*

It is proposed to provide government vehicles for the orthopaedically handicapped children at Indore and Raipur with a view to enable local handicapped children to get the benefit commuting to the institutions.

#### *Other Decisions During the IYDP.*

During the IYDP, the state government has taken the following further decisions for the welfare of the handicapped:

1. Three per cent reservation for handicapped in class III and IV services under the state government.
2. Ten years age relaxation to handicapped persons for entry in a government service.



3. The destitute handicapped will receive social security pension of Rs. 60 per month irrespective of age.
4. Voluntary organisations will receive 100 per cent grants-in-aid for the salary of teachers.
5. All the handicapped persons in the state in need of artificial limbs will be given financial assistance for the purpose.

### PROBLEMS

It will be seen that although the state government has opened a number of institutions for the welfare of the handicapped persons, the services are meagre and benefit only a small section of the handicapped population. The main hurdle in extending the benefits to a larger population is shortage of funds. However, within the limited financial resources, all efforts are being made to expand and promote the welfare schemes. Voluntary organisations also find it difficult to raise funds to meet the expenditure. The handicapped people, mostly coming from backward and poor classes, are not in a position to contribute anything for the services rendered to them and the people in most of the areas being themselves poor cannot be expected to come forward for their assistance in a big way.

The existing services mostly cover education and training and therefore no institution has become self-sufficient so far. One another difficulty faced is that of unsuitable buildings. The expenditure on construction of buildings is very heavy. Only three voluntary organisations in the state, namely, M.P. Drishtihin Kalyan Sangh, Indore, Madhav Andhashram, Gwalior, and Mook-Badhir Andhashala, Indore, have received assistance from the Government of India for construction of buildings. They are expected to bear the burden of 10 per cent of the total expenditure from their own resources. Even this appears to be beyond their reach. Government institutions face a similar problem.

Another difficulty is that of trained teachers who are not available in the state. There is no institution in the state to train teachers to reach the blind, the deaf and the mentally retarded. The result is that the present institutions are under-staffed or have unqualified teachers.

The problem of non-availability of braille books has already been mentioned earlier.

### CONCLUSIONS

Despite these problems, the state is committed to the welfare of its poor people generally, and of the disabled persons particularly. The social security pension scheme, 1981, provides for a monthly pension of Rs. 60 a month to every disabled person of whatever age, if he has nobody to look after him. This has come as a great boon and solace to the handicapped



persons of the state. As most of the helpless handicapped live in rural and backward areas and cannot easily take to jobs, this pension at least gives them a way out for their living. A campaign to carry to the disabled the message of 'participation with dignity', is also on, with an assurance that the state will do everything possible to relieve their suffering. More schemes are likely to be formulated in the light of the comprehensive survey that is going on and the results of which are likely to be available soon.

—*Social Welfare Department, Government of Madhya Pradesh, Bhopal.*

## Manipur

As per the national plan of action for IYDP, the state has drawn up a separate state plan for implementation of various schemes envisaged therein. The state government has constituted a fifteen member state level committee with four co-opted members. The chief secretary is chairman and the director (SW & AC) is member-secretary. This committee is to find out ways and means to carry out the schemes in respect of the disabled persons during the year.

The state plan of action envisages the following on a priority basis:

Helping disabled persons in their physical and psychological adjustment to society by defraying a reasonable part of their expenditure in this regard.

Promoting regional efforts to provide disabled persons of all categories with proper assistance, training, care and guidance to make available opportunities for suitable work and to ensure their full integration in society.

To encourage study and research projects designed to facilitate the practical participation of disabled persons in daily social life by accelerating their access to public gatherings and transportation system.

Educating and appraising the public of the rights of disabled persons to participate in and contribute to economic, social, and political life.

To promote effective means of prevention of disability and to rehabilitate disabled persons.

As per the national plan, Manipur has been pursuing a detailed plan of integrated education for the handicapped. Arrangement for the teaching of 50 orthopaedically handicapped school children has been started simultaneously with the inauguration of IYDP. A sum of Rs. 50,000 has been earmarked in the budget for the purpose. The state government is arranging to extend recurring financial assistance to educational institutions working for handicapped persons, covering both governmental and voluntary organisations, both in the valley and in the hills. A specific provision has been made available for this scheme.



Further, proper arrangements for economic and social rehabilitation of the disabled persons have been made providing artificial limbs, white cane, wheelchair, exercise cycle, etc. A sum of Rs. 20,000 has been earmarked for the purpose. Besides, six resource rooms for disabled students have been proposed to be opened both in the valley and in the hills (4 schools in the valley and 2 in the hills for the average of 8 students per school). The state level committee in its meeting in May 1981 decided that the state labour department be requested to open special counters at district employment exchanges at an early date.

The state committee has also decided to promote and establish sheltered workshops for multiple handicapped persons, providing financial assistance, and, if possible, to set up model workshops in all the districts of the state.

Further, reservation of 3 per cent of posts for disabled persons in the lower grades of the government posts was also discussed for implementing in a phased programme as envisaged in the directive of the Government of India.

The state government is strengthening the machinery for inspection and supervision of the activities of voluntary organisations in the field by creating suitable posts of inspectors and other staff with a view to creating more employment facilities for the disabled. The state level committee has also decided to extend more benefits to disabled persons in the field of agriculture, poultry farming, piggery, animal husbandry and small industries.

—*Directorate of Social Welfare, Arts and Culture, Government of Manipur, Imphal.*

## Meghalaya

Meghalaya celebrates IYDP along with the rest of the country by organising rallies, games, sports, musical competitions, etc., for disabled persons. Public meetings are also held in order to focus the attention of, and bring awareness to, the public about the problems of the physically handicapped in the state. About 500 physically handicapped had participated in the celebration of IYDP at Shillong and Tura.

### SCHEMES FOR THE WELFARE OF THE HANDICAPPED

The department of social welfare is implementing the following schemes for the welfare of the physically handicapped in Meghalaya.

#### *Prosthetic Aids*

Financial assistance is given for purchase of appliances, artificial limbs



like crutches, tricycles, spectacles, hearing aids, etc. Thirty-three physically handicapped persons have so far received prosthetic aids from the government.

#### *Scholarships*

Scholarships are being given to the physically handicapped students reading in schools/colleges in or outside the state. At present 110 students are receiving these scholarships.

#### *Token Relief Grants*

Financial assistance is given to the physically handicapped who are very needy and want to earn their livelihood by starting small shops like *pann biri*, etc.

### SURVEY OF THE HANDICAPPED

A survey of the physically handicapped is being conducted in the state to find out the population of different types of physically handicapped persons and their problems so as to enable the state government to plan effective programmes for them. The survey is expected to be completed late in 1981 or early 1982.

Assistance to physically handicapped persons for vocational training/self employment: This is a new scheme and is being implemented from this year. Deserving physically handicapped, who are willing to undergo vocational training for self-employment, will be given financial assistance.

Organisation of seminars/workshops on special problems of the handicapped: A state level seminar is being organised at Shillong on the special problems of the handicapped.

Training of officers in physiotherapy and occupational therapy (diploma courses): The scheme has been advertised. Financial assistance from the government will be given for this purpose.

—*Office of the Director of Social Welfare,  
Government of Meghalaya, Shillong.*

## **Orissa**

Orissa has a population of about 200,000 handicapped as given by the bureau of statistics and economics on the basis of a detailed survey made in 1965-66. Before the setting up of the social welfare department in 1975-76, the programmes for the welfare of the disabled were dealt with by different departments of the government. The CD & RR department, after taking over the programmes for the handicapped welfare, has extended the



following facilities to disabled persons and is trying its best to enhance the scope gradually within its limited resources.

- The state government is sanctioning scholarships to the physically handicapped students from class IX to university level on behalf of the central government. Besides, the state government has its own scheme of scholarships from class I to class VIII for those not covered by the Government of India scholarship scheme.
- The state government has reserved 3 per cent of the vacancies in class III and IV posts/services of the government and public undertakings. An employment cell has been opened in CD & RR department to register the names of the disabled persons and issue identity cards against registration. When the vacancies are communicated to the department, candidates registered under the cell are sponsored for appointment against the vacancies. Besides, there is a special employment exchange for the physically handicapped under the housing and labour department which is also registering handicapped persons for employment.
- There is a scheme of special aids for handicapped persons of different categories. Financial assistance is given to the poor and needy handicapped persons on the recommendation of medical experts and when sponsored by voluntary organisations, government hospitals, and CDMOs.
- A scheme for self-employment is going to be introduced soon. In this scheme, there is provision of 50 per cent subsidy to the handicapped persons who would take up a trade or some other vocation.
- The voluntary organisations working in the field of handicapped welfare are given financial help in the shape of grants-in-aid. Voluntary organisations that apply for Government of India grant for welfare activities of the handicapped under the scheme of assistance to voluntary organisations are recommended to the Government of India after proper inspection.
- A school for the mentally retarded children has been opened in the state with financial help from the state government.
- In order to rehabilitate handicapped persons, voluntary organisations are helped to start vocational training centre-cum-sheltered workshops in the state. A proposal to open one such centre in each district is under active consideration of the government.
- The state government has extended facility of a conveyance allowance of 10 per cent of the basic pay of the state government employees subject to maximum of Rs. 50 per month specially to the orthopaedically handicapped and the blind.
- The state government has granted a concession of 50 per cent bus fare to the blind in government buses.





- The state government is considering the introduction of a scheme for 'disabled pension and unemployment allowance' to the handicapped persons.
- The state government is implementing a scheme of integrated education of the disabled since 1976-77. So far 12 schools have been opened covering 190 students and it is being financed on a 50:50 basis by the state and Central government. Recently, Government of India have decided to finance the scheme on a cent per cent basis.

The state government in CD & RR department with the help of other departments, has achieved considerable success in implementing the above welfare programmes of the handicapped. These schemes have always been kept in view as an integral part of the state economic and social development plan.

As regards the organisational and implementation problems the following points may be mentioned.

It has not been possible to have an adequate survey of the handicapped population in the state at present. So it is not possible to know the magnitude of the problems of the handicapped.

The policy of the state and Central government is to encourage voluntary organisations to take up welfare activities of the disabled. But an adequate number of voluntary organisations are not coming up to take up these welfare programmes. Public donations in this field are not forthcoming. So those who take up welfare activities always depend upon the state and Central governments to be financed fully to run their programmes.

The resources of the state government are too limited to take up new ventures for the welfare of the handicapped. The provision under the plan and non-plan sector is not adequate to accommodate the different schemes.

There is no organisational set-up from the *gram panchayat* to the *district level* to look after the problems of the handicapped. At the state level a special officer (handicapped) is the only one officer to look into all matters pertaining to the welfare of the handicapped. He has not been given secretariat status; as a result it is not possible on his part to inspect voluntary organisations and recommend their cases for financial assistance from the Government of India.

A state level committee on IYDP has been formed with the minister for state, CD & RR as chairman and the deputy minister CD & RR as vice-chairman. This committee has representatives, both official and non-official, from various departments of government and voluntary organisations dealing with handicapped welfare.

This committee acts as an advisory body to the state government on the formulation of objectives, priorities and programmes of action for the observance of IYDP. And the committee reviews the progress from time to time. The tenure of the committee is initially for 2 years which would be



extended if necessary. The committee met in December 1980 and in July 1981 and recommended strengthening the primary health centre in each district for identification of disability; organising safety campaigns for prevention of accidents causing disability; strengthening nutrition programme to cover all children between 0-2 age group, specially in tribal areas, for prevention of malnutrition causing disability; establishment of a braille press for supply of braille books to the blind students; publication of literature to remove barriers of prejudices and discrimination against the disabled and project their healthy image in the society; establishment of more integrated units in educational institutions for the normal children.

—*The Community Development and Rural Reconstruction Department, Government of Orissa, Bhubaneswar.*

## Sikkim

According to the provisional survey report 1981 of disabled persons (with the type of disability), as released by the Census Department, Government of India (Sikkim branch) the following are the numbers of disabled persons in Sikkim. Totally blind 182; totally crippled 360; and totally dumb 1,940.

However, a scientific survey of disabled persons is yet to be conducted covering bio-data and family background, socio-economic adjustment, attitude of the family and the community towards disabled persons, etc. It is learnt that as per the directive of the United Nations, Bureau of Economics and Statistics, the Government of Sikkim is to conduct a comprehensive survey of the disabled in the state from July 1981 and for which the state government has already accorded approval. It is hoped that the treatment and rehabilitation of disabled persons would be based on the result of the proposed survey.

Following the declaration of IYDP this year, the Social Welfare Department is taking up the following measures for training and rehabilitation of the handicapped people.

- Opening of a sheltered workshop in south Sikkim where initially about a dozen handicapped persons (blind and crippled) will be engaged. Work will begin with cane and bamboo and light engineering; other small scale trades will be introduced gradually.
- Opening a blind school for which action is initiated by the education department.
- Granting of stipends to the blind, deaf and dumb, etc., for their education in institutions outside Sikkim.



- Granting of stipends and other facilities to the extremely poor handicapped children for their education.
- Supply of text books on subsidy.
- Free transport facilities to the handicapped.
- The establishment department is taking action for job reservation for the handicapped.
- Free supply of prosthetic equipments to the handicapped.

The above schemes are formulated keeping in view the resources of the Social Welfare Department which is Rs. 5 lakhs only for 1981-82.

—*Social Welfare Department,  
Government of Sikkim, Gangtok.*

## **Uttar Pradesh**

The Social Welfare Department was set up in 1955 and the scattered welfare schemes/services were integrated and the welfare programmes for the benefit of the disabled are being conducted by the department in the following manner.

### **EDUCATION, TRAINING AND REHABILITATION**

#### *Deaf and Dumb*

Three deaf and dumb schools are being run at Agra, Bareilly and Farukhabad. Education up to high school standard is imparted in these schools. The capacity of these schools is 100-150 students. In all these schools boarding for the students is available. In addition, students whose parent's/guardian's monthly income is below Rs. 500 are granted scholarships at Rs. 100 per month. In Agra there is a training centre for the deaf and dumb and a workshop is attached to it. Residential accommodation is available in it for 50 residential trainees and lodging expenses at the rate of Rs. 100 per residential trainee are borne by the state government.

#### *Blind*

Three blind schools are run at Lucknow, Gorakhpur, and Banda. Education up to high school is imparted in these schools and the blinds are rehabilitated after training in various trades. At Lucknow, Gorakhpur, and Banda three attached workshops are also being run for the blinds. Here jobs are got made to the blinds on the basis of work-orders; they are paid wages for their work. There is provision for payment of non-working allowance at the rate of Rs. 2 per day for the day they do not get any job. For blind girls a school is being run at Saharanpur where education



up to junior high school is imparted and residential facility is also available here. For blind girls, there is a training centre and attached workshop at Gonda. Its strength is 100 girls and here they are given training in different trades.

#### *Mentally Retarded*

At Lucknow and Allahabad residential schools, one each, is being run to impart education in a psychological manner to mentally retarded children. The capacity of each school is 50 children. In these schools, in addition to imparting education, there is provision for occupational training. Government incurs an expenditure of Rs. 100 per month per student on lodging. The students whose parent's/guardian's monthly income exceeds Rs. 400 have to bear the lodging expenses themselves.

#### *Physically Disabled Handicapped*

Two residential schools with a capacity of 50 students each are being run at Lucknow and Pratapgarh districts. In these schools expenditure in connection with the lodging of the students is borne by the government. Education up to high school standard is imparted. For the training of physically handicapped persons two attached workshops are being run at Allahabad and Mirzapur. Here residential accommodation is available for 50 and 40 trainees, respectively. In these workshops training in various vocations is given. After training, the residents are provided job/work on a work-order basis. The capacity of each is 100 co-residents. For disabled persons, a multipurpose attached workshop and production centre have been set up in Unnao district. There is facility here for training in different trades. The capacity of this workshop is 100 persons, out of whom 50 are provided free boarding and lodging and 50 non-resident inmates are provided with jobs in the workshop in different occupations on the basis of work-order.

### PUBLICITY

To spread information regarding facilities available to the disabled, there is arrangement for publication of literature regarding education/training of handicapped/disabled and other related programmes.

### AWARDS

Grants of awards in Uttar Pradesh at state level to outstanding disabled workers, self-employed disabled persons, employers of the disabled and placement officers are in vogue.

#### *For Employers*

- (a) Shield or *Tamra Patra*
- (b) Merit Certificate

*For Outstanding Disabled Workers*

- (a) Cash Award of Rs. 1,000
- (b) Merit Certificate
- (c) Certificate
- (d) Badge of any Metal

*For Outstanding Placement Officers*

- (a) Shield
- (b) Certificate
- (c) Merit Certificate

**SCHEMES FOR GRANTS***Personal Grant*

1. Provision for a maximum grant of Rs. 500 per head to physically handicapped persons for purchase of artificial limbs, hearing aids, wheel-chairs, tricycle and spectacles.

2. Provision for scholarship to handicapped boys/girls (whose parent's/guardian's total income does not exceed Rs. 500).

3. Scholarship to boys/girls whose parents are handicapped (whose parent's/guardian's total income does not exceed Rs. 500).

4. Financial assistance at the rate of Rs. 50 per head to destitute handicapped persons.

*Grant to Voluntary Organisations*

Provision for grant of assistance to voluntary organisations engaged in activities for the welfare of the handicaps.

The state labour department is responsible for:

*Special Cell in Employment Exchanges*

Setting up of special cells in the employment exchanges in the state at Lucknow, Varansi, Agra and Allahabad for employment of the handicapped.

*By All Employment Exchanges of the State*

Getting employment by sponsoring the names of handicaps for vacant posts.

To provide assistance in vocation selection by rendering/giving vocational advice in the context of educational qualification, vocational competence, family background and specified physical ability.

To encourage self-employment and rendering of assistance in getting loans from banks.

For running desired vocation/occupation, providing of relevant information in regard to vocations/occupations.



*Special Employment Exchange for the Handicapped, Kanpur*

Registration of handicapped applicants, sponsoring their names to employers for selection, employment, vocational and industrial training, vocational guidance and providing assistance in matters relating to medical examination by the medical board, etc.

Coordination between all employment exchanges of the state engaged in work relating to employment to registered handicapped persons.

Collection and compilation of statistics in regard to handicapped persons at state level and making available the same to concerned persons/institutions.

As a forward plan, the education department is making efforts for the coordinated education of the handicapped persons from next session in five selected cities of the state.

The medical and health department of the state offers the following facilities:

Bringing handicapped persons to the district hospitals in urban areas and to primary health centres in urban areas by the field officers of medical health and family welfare and revenue department for free medical examination and taking necessary treatment.

Effective contribution of the officers of the medical health and family welfare department in preparation of the lists of handicapped persons through tehsildars.

Chief medical officers are making sample check of the lists of the handicapped persons which would be made available to the district hospitals and primary health centres.

From March 1, 1981 to March 15, 1981 at all district hospitals and primary health centres, (keeping in view the nature of the medical aid required) the handicapped persons were examined medically and were provided medical aid, after preparation of appropriate statements.

Provision of a separate counter for handicapped persons and laying of information boards displaying medical facility available to handicapped persons at all district hospitals and primary health centres.

To prevent diseases of eyes and ears, scheme/programme for medical examination and health education to all school going children in all the districts.

For recruitment of handicapped persons to the services/posts under the state, age relaxation is provided.

For travel in buses 50 per cent concession in the normal fare is granted to blind and physically handicapped passengers. However, passenger tax and other taxes imposed by local bodies are charged.

This facility is available at every bus stand at the time of purchase of ticket. In city buses this facility is available from the conductor at the time of travel in local buses.

With a view to provide employment to handicapped persons a



reservation of 2 per cent has been provided for handicapped persons in class I, II, III and IV posts under the state government.

To make the blind, deaf and physically handicapped persons earn their livelihood local bodies have reserved 10 per cent shops for them.

—*Social Welfare Department, Government of Uttar Pradesh, Lucknow (Translated from Hindi by Prem Prakash Kalra, Translator, Department of Personnel and Administrative Reforms, Ministry of Home Affairs, New Delhi.)*

## **West Bengal**

In observing IYDP, the Government of West Bengal has laid stress on the economic and social rehabilitation of the disabled and on creating an awareness among the people towards their problems. The object is integration rather than segregation of disabled persons.

The state has set up a 'handicapped board' to coordinate the plans and programmes connected with the welfare of physically handicapped and mentally retarded persons. This board consists of eminent physicians, social workers, representatives of reputed voluntary organisations and heads of the departments of the government concerned with the matter. The main function of the board is to create and sustain public awareness of the needs of the disabled; to coordinate and integrate the activities of government departments and voluntary organisations in this field and to review periodically the progress made under different programmes; to locate gaps in the existing services; to suggest measures for improvement; and also to formulate fresh schemes for the welfare of the handicapped.

In order to observe IYDP in a befitting manner, a steering committee headed by the Governor of West Bengal has been set up with ministers-in-charge of the concerned departments as members. IYDP began with a formal inauguration in April, 1981 with the chief minister in the chair, a large number of distinguished people including representatives of voluntary organisations and also a huge gathering of disabled persons. Earlier, during the year the governor, the chief minister and several other ministers addressed a rally of disabled persons and launched the programme of creating public awareness of the needs of physically handicapped and mentally retarded persons. Separately, a seminar was held in Calcutta where notable personalities from all walks of life participated in the discussion of the problems of the disabled and their solution.

### **MEASURES FOR THE WELFARE OF THE HANDICAPPED**

The state government has so far adopted the following measures for





the welfare of the handicapped. No general definition of the disabled is adopted. Their definition varies for different welfare schemes.

#### *Prosthetic Aid*

The object of the scheme is to enable the handicapped to earn their livelihood independently. Different aids and equipments, namely, hearing aids, artificial limbs, wheelchairs are given to the orthopaedically handicapped, the blind, the deaf and dumb persons, free of charge. Fittings are also done free of charge by experts. Such aids are given to persons whose future rehabilitation is feasible, and 1,580 persons have been benefited under this scheme.

#### *Scholarships to Physically Handicapped Students Studying*

The scheme provides for financial assistance to the needy physically handicapped students studying below class IX in recognised educational institutions with a view to helping them to acquire such academic skill at secondary stage as will enable them to go in for higher studies; 423 students are benefited. From class IX, the education department bears the expenditure; 319 students are benefited. Students whose family income is below Rs. 500 per month are given a stipend of Rs. 25 each per month up to class V and of Rs. 30 each per month in classes VI and VII. Additional allowance of Rs. 20 each per month is given to orthopaedically handicapped students necessitating special arrangement for transport to and from the institutions. Readers' allowance of Rs. 20 each per month is allowed to blind students.

#### *Disability Pension*

This scheme provides for grant of a pension of Rs. 20 per month to the destitute physically handicapped persons who are incapable of earning a living and are declared as such by a government medical officer. Over 1,750 persons have benefited so far and the target beneficiary of 2,780 is expected to be fulfilled in 1981.

#### *Economic Rehabilitation of the Physically Handicapped Adults*

The object of the scheme is to provide financial assistance to the physically handicapped adults belonging to families in low income group to help them set up small scale industrial units, poultry, dairy, piggery, etc. The amount of grant is limited to Rs. 1,000 per disabled adult, 90 per cent of which is paid in kind.

#### *Vocational Training*

Government has decided to set up vocational training centres for the handicapped in Calcutta and all district headquarters. Such centres may also be established by voluntary organisations with government assistance.



In West Bengal a notable voluntary organisation, namely, Rehabilitation India, has established a sheltered workshop for the handicapped. Another organisation named Rehabilitation Centre for Children has also started very good work in this line. The state government also runs two vocational training centres and one agricultural training centre for the disabled.

#### *Special Education*

The Government of West Bengal runs five schools for the blind. Besides, voluntary organisations have established a number of schools for the blind, deaf and dumb and mentally retarded persons.

#### *Preventive Measures*

The Government of West Bengal has given serious consideration to the measures for prevention of disability. Since malnutrition and vitamin and iron deficiencies are the main causes of various disabilities, the government has taken up a special nutrition programme for children of the age group 0-6 years and for the nursing and expectant mothers. They are given nutritious food and health check-up and immunisation. The number of beneficiaries at present under this programme is about 1.2 million. Besides the special nutrition programme, approximately 200,000 people are covered under twenty intensive child development schemes. The programme provides for a package of services to children below six years of age. Pregnant women and nursing and expectant mothers in these blocks are also given supplementary nutrition and health education. Besides, mother and child care programme is continuing in 30 blocks with the assistance of UNICEF and CARE. Children up to 6 years and nursing and expectant mothers are provided nutritious food and health inputs. There are 50 feeding centres and 50 child care centres in each block. The number of beneficiaries in these blocks is approximately 300 thousand.

#### *Reservation of Vacancies*

The Government of West Bengal has reserved 2 per cent of the vacancies in all offices, establishments and industries under it for physically handicapped persons. For implementing the scheme there is a monitoring cell under the labour department of the government. Besides, it has been ordered that irrespective of the number of vacancies in an office during 1981, at least one disabled person has to be given a job in each office.

—*Relief and Welfare Department,*  
*Government of West Bengal, Calcutta.*

## Invisible disabilities

A high proportion of impairments and disabilities are the end-result of an absence of knowledge or medical attention about common diseases or at-risk health conditions. Some such conditions are not conventionally thought of as disabilities.

### MATERNITY-RELATED

There are 110 million births each year, 75% in developing countries, where perinatal risks are much higher and newborn have lower birth weight, itself a contributor to disability-producing sequelae. A fetus can be severely affected during pregnancy by disease in mother such as rubella, syphilis. Complications during delivery can also damage newborn. 0.5% world population disabled in these ways.



ICEF 7221

### DEBILITY

Certain diseases reduce a person's productive life by around 15%, and are indirectly disabling. Examples: malaria: cause of 30% of health centre consultations in Africa; schistosomiasis (bilharzia): affects 200 million, many with severe lassitude; TB: annual risk rate is 2% in some developing countries.

### MALNUTRITION

The most severe form, protein-energy malnutrition, affects 100 million children under 5 in developing countries; it can permanently stunt growth, physically and mentally (see p.6). 250,000 children go blind each year from vitamin A deficiency (see p.10); iodine deficiency causes endemic goitre (200 million affected), sometimes leading to cretinism; iron deficiency (anaemia) also causes impairment.



ICEF 6884

### COMPLICATIONS

Some disabilities derive not from the original disease, but from its complications. Untreated scabies (skin infection) can lead to kidney malfunction, hypertension; a continual cold can lead to deafness; alcoholism and drug abuse can lead to hepatic damage, trauma from accidents, depression, anxiety.

### SECLUSION

Negative attitudes towards people with impairments, causing children to be hidden from sight, kept in dark room, deprived of stimulation and normal social contact, ostracized, constitute much graver disabilities than the impairments themselves. In developing world, this feature of social life is common, but no reliable data available on which to quantify numbers affected.

## THE ORIGINS OF PREJUDICE

The origins of prejudice have long been sought by sociologists and economists. Karl Marx explained prejudice toward the socially handicapped by elaborating his theory of capitalism as a system which produces discrepancies between well-adjusted 'haves' and weak 'have-nots'. Free enterprise has rules to make the rich and healthy even stronger, the poor and weak even weaker.

Years later Max Weber agreed partially with this economic theory but pointed out that it was insufficient to explain the roots of prejudice. Prejudice is spawned in human psychology which is reflected in the value system, culture and tradition of each ethnic group and nation.

—*Rehabilitation/World, Summer 1977.*

## Vocational Rehabilitation of the Disabled

*[As part of its contribution to the IYDP, the ILO has undertaken a world-wide survey of vocational rehabilitation legislation. The survey report may not however be available before late in the year.*

*[The document we give here, nevertheless, provides a brief overview of the main trends in vocational rehabilitation in recent years and the main policy issues confronting ILO member states and is part I of the report of the Director-General to the International Labour Conference, Geneva, 1981.]*

Disabled persons have the same hopes, aspirations and rights as everyone else. This basic and simple statement, however, is not universally appreciated, as evidenced by the fact that no country, not even in times of economic prosperity, has solved the problem of integrating all its disabled people into active social and economic life. When unemployment is rife, the disabled suffer more than most; in Third World countries their prospects of obtaining work in the open employment market are minimal or non-existent; in the industrialised countries today their rate of unemployment is often double that of non disabled workers. Cynics would say that this is merely a question of lack of opportunity for the disabled and a problem which should be examined when the economic position improves. In reality, such a short-sighted and discriminatory approach is one which fails to take into account not only the basic human rights of the disabled but also the economic benefits that would accrue to the disabled, their families and the State itself if they were to be productively employed. In human terms, it is a depressing picture, with the disabled experiencing feelings of inadequacy, dependency and insecurity, often opting out of society or turning to begging as a means of livelihood.

The magnitude of the disablement problem is not generally recognised. The minimal world figure of 450 million disabled persons (or one in ten of the world's population) is often regarded with scepticism. A closer look at the numbers affected by the most prevalent forms of disablement, however, shows just how minimal is this estimate. For example, organisations of and for the blind report that there are 40 million blind people world-wide, with many millions more at risk owing to trachoma, river blindness, malnutrition, etc. At least 70 million persons suffer from severe or total deafness. In the Third World, leprosy, poliomyelitis and tuberculosis are still major disabling conditions affecting some 60 million people. According to the World Health Organisation severe mental illness affects one person in ten at some point during his lifetime and one person in every hundred throughout life; moreover, research has shown that 3 per cent of all babies born are mentally retarded to some greater or lesser degree. The industrialised countries, with their highly developed disability prevention and health-care services, have eliminated or brought under control many incapacitating diseases, but they are faced with other and very serious causes of handicaps. For example, some 7.5 million people are admitted to hospital annually as a result of road accidents. It is also estimated that each year there are 50 million work-related accidents or 160,000 accidents every day—many resulting in permanent disability. Add to these the millions suffering from heart and circulatory diseases; drug and alcohol-



dependent persons; the surviving victims of war, polluted environment, famine, earthquake and other man-made or natural disasters and the total figure of 450 million disabled persons seems very minimal indeed.

Nor is there any indication that the problem is diminishing. On the contrary, and somewhat paradoxically, expanding and improved medical services will add to the numbers of disabled in all communities by prolonging the life of many severely disabled persons who only two or three decades ago would not have survived early childhood.

By including the subject of vocational rehabilitation of the disabled as part of my annual Report, I feel that I am echoing the growing concern of governments, employers and organised labour for greater ILO involvement in this field—a concern which has been reflected not only in the resolution concerning disabled persons adopted by the International Labour Conference in 1979 but also in Governing Body discussions of the need to up-date the Vocational Rehabilitation (Disabled) Recommendation, 1955 (No. 99), and on the ILO's role in helping to attain the aims and objectives of the International Year of Disabled Persons (IYDP) with its theme of "full participation and equality".

No organisation is better placed than the ILO to help achieve the five principal objectives of the International Year. These objectives are aimed at encouraging the rehabilitation of the world's 450 million disabled by—

- helping disabled persons in their physical and psychological adjustment to society;
- promoting all national and international efforts to provide disabled persons with proper assistance, training, care and guidance, to make available opportunities for suitable work and to ensure their full integration in society;
- encouraging study and research projects designed to facilitate the practical participation of disabled persons in daily life, for example by improving their access to public buildings and transportation systems;
- educating and informing the public of the rights of disabled persons to participate in and contribute to various aspects of economic, social and political life;
- promoting effective measures for the prevention of disability and for the rehabilitation of disabled persons.

Vocational rehabilitation services should provide the starting point from which persons with disabilities can attain social and economic independence and the self-respect and dignity which go with them. Recommendation No. 99 stresses that vocational rehabilitation services should be made available to all persons, whatever the origin and nature of their disability. The right of the disabled to secure and retain employment is embodied in the Declaration on the Rights of Disabled Persons adopted by the United Nations General Assembly in December 1975. But declarations in themselves are not sufficient; the political will and means to implement them must be found if the International Year of Disabled Persons is to have any meaning at all.

There are many factors militating against the integration of disabled people into active working life. Lack of recognition on the part of planners of the economic consequences of leaving the disabled to fend for themselves has already been mentioned. Add to this popular prejudice directed against the disabled in general and certain groups in particular (*e.g.*, the mentally handicapped, leprosy patients); the changing nature and patterns of work with increasing automation and mechanisation often resulting in decreased rather than the anticipated increased job opportunities; a rapidly growing labour force and mass movement from rural to urban areas in Third World countries; the gradual breakdown of the traditional system of family care and support for the disabled—all these and other social, economic and demographic trends have important implications for the future development of vocational rehabilitation services for the disabled.

The report which follows traces the development of ILO vocational rehabilitation activities over the years, the particular problems encountered and the strategies which



have been devised to combat them. It also looks ahead to the planning of a long-term programme of action associated with the aim and objectives of the International Year of Disabled Persons, with possible new approaches suggested for the creation of job opportunities for one of the poorest and most underprivileged sectors of society.

## THE ILO'S CONTRIBUTION TO THE VOCATIONAL REHABILITATION OF DISABLED PERSONS

### *First Steps*

The ILO's first initiative in the field of vocational rehabilitation was the publication in 1921 of a report on attitudes towards the compulsory employment of disabled ex-servicemen. This documentary study was followed in 1923 by the convening of a meeting of experts in Geneva to study methods of finding employment for the disabled.

It is interesting to note that the conclusions of this expert group—which constituted one of the first international meetings of its kind on vocational rehabilitation of the disabled—still have some relevance today for many countries, with the exception that they should be applied to all disabled persons, not just to disabled ex-servicemen. They stated that disabled ex-servicemen should have the opportunity of earning their livelihood, independently of any pension received, by their own productive work to the fullest extent of their capacity, and that the State was pre-eminently responsible for legislating and devising means for the employment of disabled ex-servicemen.

The conclusions reached by this meeting and the draft legislative provisions it prescribed led to the first international recognition in 1925 of the vocational needs of disabled persons when the session of the International Labour Conference of that year included provision for the vocational re-education of injured workmen in the Workmen's Compensation (Minimum Scale) Recommendation (No. 22).

Further progress at the national and international level was hindered during the 1930s by the world-wide economic recession; but the Second World War brought the question of rehabilitation of the disabled sharply into focus again when large numbers of war-disabled persons required intensive rehabilitation care and when the civilian disabled filled the serious manpower gaps in industry and commerce to such good effect. This latter development, more than any other in recent years, demonstrated conclusively to employers and the disbelieving public at large that the disabled, through vocational rehabilitation, can undertake successfully the widest range of work from the unskilled to the highest professional level. It also demonstrated beyond any doubt that disability in itself need not be a handicap to integration into normal work settings.

No doubt, the session of the International Labour Conference which met in Philadelphia in 1944 was also impressed by the fine work performance of the disabled during the war years, for it reaffirmed in the Employment (Transition from War to Peace) Recommendation (No. 71) that disabled workers, whatever the origin of their disability, should be provided with full opportunities for rehabilitation, specialised vocational guidance, training, retraining and employment on useful work. These international standards provided a concise list of steps considered essential for the return of a disabled person to employment (*i.e.*, the criteria for selection, collaboration with other related services, vocational guidance, vocational training, placement services and sheltered work) and formed the basis for postwar vocational rehabilitation legislation in several European countries. But as the ILO Committee of Experts on the Application of Conventions and Recommendations pointed out in 1952 when examining reports and information under articles 19 and 22 of the ILO Constitution, Recommendation No. 71, as its title indicated, was designed to cover a transitional period only. Insofar as vocational rehabilitation was concerned, it was recognised that such a subject could not continue to be dealt with piecemeal in Recommendations dealing with much broader social and economic issues, but warranted a separate set of standards which would make clear the need for a continuous, conordinated





delivery of vocational rehabilitation services and the administrative machinery on which such services should be based.

*Vocational Rehabilitation (Disabled) Recommendation, 1955 (No. 99)*

On 22 June 1955 the International Labour Conference unanimously adopted the Vocational Rehabilitation (Disabled) Recommendation (No. 99). The adoption of this instrument was not only a landmark in the development of international interest in vocational rehabilitation of the disabled but also acted as a stimulus to national activity in this field. Though directed to governments, it has also provided the means whereby any agency or non-governmental organisation could refer to what are internationally regarded as the essential elements of vocational rehabilitation and how to apply them in practice. Judging by the number of countries known to have revised or extended their vocational rehabilitation law and practice or to have introduced legislation for the first time over the past 25 years, it seems clear that the terms and spirit of the Recommendation have made a substantial impact in many parts of the world.

The influence that this instrument has had and still continues to exert on vocational rehabilitation activity throughout the world is such that it is worth recalling its definitions and main provisions:

- 'vocational rehabilitation', for example, is defined as "that part of the continuous and coordinated process of rehabilitation which involves the provision of those vocational services, *e.g.*, vocational guidance, vocational training and selective placement, designed to enable a disabled person to secure and retain suitable employment";
- the term 'disabled person' is defined as "an individual whose prospects of securing and retaining suitable employment are substantially reduced as a result of physical or mental impairment".

The Recommendation, significantly, applies to all disabled persons, whatever the origin and nature of their disability. The guidance it provides covers the essential elements and scope of vocational rehabilitation, the principles and methods to be applied to the vocational guidance, vocational training, placement and follow-up of the disabled, as well as an outline of the administrative organisation of vocational rehabilitation services and methods of enabling disabled persons to make use of these services. It deals with co-operation between the bodies responsible for medical treatment and those responsible for vocational rehabilitation. There are special provisions for disabled children and young persons.

Two Parts of the Recommendation deal with the important questions of employing the disabled: methods of widening employment opportunities are indicated; close cooperation with employers' and workers' organisations to promote maximum employment opportunities is recommended; the need to stress the abilities and working capacities of disabled persons, not their disabilities, and to afford them an equal chance with the non-disabled to perform work for which they are qualified, is emphasised; means of providing employment and encouraging the creation of cooperatives or similar enterprises of disabled persons are discussed; and sheltered employment in special workshops or through home-work schemes receives special attention.

Finally, the Recommendation stresses that vocational rehabilitation services should be adapted to the particular needs and circumstances of each country and should be developed progressively with the aim of promoting and improving employment opportunities for the disabled.

Resolutions recalling the provisions of the Recommendation and reaffirming its importance were adopted by the 1965 and 1968 Sessions of the International Labour Conference. The latter resolution called for appropriate studies to be made to determine to



what extent, if any, Recommendation No. 99 needed to be revised. Studies were subsequently carried out in 1970 and revealed that the majority of member States considered that the basic principles embodied in Recommendation No. 99 were still valid.

A resolution adopted by the International Labour Conference at its 60th Session in 1975 was significant in that it introduced for the first time the concept that the ILO's vocational rehabilitation activities should be aimed at the social as well as the vocational reintegration of disabled persons. The same resolution stressed that a high proportion of disabled persons in society constituted a serious drain on the national economy and could undermine the prosperity of a country—and therefore the welfare of its people—unless effective measures were taken. The resolution also called in all public authorities and employers' and workers' organisations to promote maximum opportunities for disabled persons to perform, secure and retain suitable employment.

The most recent resolution adopted by the International Labour Conference concerning disabled persons (65th Session, 1979) was aimed at ensuring that the ILO played a full role in helping to achieve the aims and objectives of the International Year of Disabled Persons. It also raised again the question of revising Recommendation No. 99—a question which the ILO Governing Body considered at its 214th (November 1980) Session and decided to include in the agenda of the Conference in 1982 under the double-discussion procedure. The Conference will therefore have an opportunity next year to examine the whole question in some detail. The pages which follow provide a brief overview of the main trends in recent years and the main policy issues confronting member States.

## VOCATIONAL REHABILITATION DEVELOPMENTS IN THE POSTWAR YEARS

### *Legislation*

An international study on rehabilitation legislation in which the ILO participated, together with the United Nations and the WHO, was undertaken in the early 1970s. The study revealed that there was a trend towards comprehensive rather than piecemeal legislation for the provision of rehabilitation services in most industrialised countries but showed little evidence of this in developing countries. It was, of course, a period of relatively full employment in the industrialised world and the implementation of legislation was geared towards integrating the disabled into the open employment market wherever possible. There were the first signs, however, that all was not well with traditional systems of sheltered employment, often based on outdated products and incurring heavy losses. In Latin America several countries were developing vocational rehabilitation within the context of social security programmes and similar benefit systems. In a number of countries with state rehabilitation programmes, the different services tended to be organised on several levels of governmental authority, including more than one ministry, interdepartmental committees, advisory councils and similar bodies. Everywhere, a growing need was felt to devote more resources for research into the rehabilitation problems of hitherto neglected groups such as the mentally ill, mentally retarded, cerebral palsied and paraplegics.

Some of these trends have continued through the seventies; but there have been other significant developments too which have found form in recent statutory provisions.

As part of its contribution to the International Year of Disabled Persons, the ILO is currently undertaking a world-wide survey of vocational rehabilitation legislation. From the information so far furnished, several new legislative measures can be singled out. One major new development is the introduction of legislation which protects disabled persons against discrimination and other forms of unjust treatment (*e.g.*, in Canada, Federal Republic of Germany and United States). Among the new types of statutory safeguards is the right of disabled students to free and appropriate public education, including pre-vocational education. Under such legislation, the State must provide specially designed instruction to meet the unique needs of a handicapped student, including all necessary related services such as developmental, corrective and supportive aids, assessment and



counselling services, etc. The right of physical access is also the subject of legislation and its implementation means that governments are beginning to insist on the removal of architectural barriers in buildings, transport and other public facilities which debar large numbers of physically and sensorially handicapped persons from active social and working life.

In the area of employment, anti-discrimination legislation stipulates that employers may not refuse to hire or promote handicapped persons solely because of their disability. For example, such refusal on the grounds of a physical handicap is recognised as discrimination in matters of employment in the human rights legislation of the following Canadian jurisdictions: Federal, Manitoba, New Brunswick, Nova Scotia, Prince Edward Island, Quebec and Saskatchewan. Similarly, in Quebec, refusal on the grounds of mental handicap is deemed to constitute discrimination. Parallel to the right of disabled persons to protection against discrimination is the new responsibility placed on employers, generally both in the public and private sector, to develop positive policies or affirmative action plans for hiring, placing and promoting handicapped individuals as employees in their establishments.

Another important new development that is reflected in legislation on the integration of disabled persons is the variety of provisions for the adaptation of the working environment (*e.g.*, in Federal Republic of Germany, Sweden, United Kingdom and USSR). These include the supply of assistance devices and other adjustments for persons with existing physical or mental impairments, as well as the protection of residual capacities of moderately impaired persons through technical, financial and other means, for example the appropriate adaptation of workplaces for workers with sensorial limitations or those suffering from particular risks of disability aggravation. The new legislation linked to other statutes relating to disability prevention, control of work accidents, work safety and health for all workers. The significance of this new approach lies in the growing recognition that in a depressed employment market there is a greater need than ever to safeguard the jobs of those workers who become, or are at risk of becoming, disabled. The new provisions draw closer together the measures concerning disability prevention, reduction of disability aggravation, and rehabilitation. Most importantly, they represent a new perspective on the safeguarding and adaptation of the working environment for all workers. The idea is that a range of services, of which rehabilitation is only a part, offers the best prospects for integrating disabled persons into work processes alongside their able-bodied colleagues.

Most quota schemes still have penalty clauses under which employers who do not achieve the stipulated percentage may be obliged to pay a fine. In some countries, the contributions that are thus collected are placed in a fund from which additional rehabilitation services, including sheltered workshops, can be financed or supported.

Some countries have adopted legislative measures for the purpose of decentralising, coordinating or streamlining vocational rehabilitation services. In Denmark, for example, vocational rehabilitation services were recently decentralised from national to local government control under a Social Assistance Act. In France an Act of 30 June 1975 provides for a coherent approach to prevention, care, education, vocational training and guidance, employment, as well as the guarantee of a decent minimum income and social reintegration. To ensure that this approach is developed on coordinated lines with the fullest possible community involvement and that of the disabled themselves, an interministerial committee for training and rehabilitation, assisted by a national consultative council, has been established. In the United Kingdom streamlining of the administration of vocational rehabilitation services was effected under the terms of the Employment and Training Act of 1973, which established the Manpower Services Commission with its two executive branches—the Employment Service Agency and the Training Services Agency—responsible for providing specialised guidance, training and employment services for disabled persons.

New legislative measures have been introduced to ensure that state control of placement procedures is more effective. For example, in some countries, regulations ensuring



coordination between social security and employment departments on questions affecting employment of handicapped persons have been introduced. In this connection, trial work periods, refresher courses and similar arrangements have been introduced to offset work disincentives of some benefit systems.

A considerable amount of new legislation deals with the organisation and working conditions of special workshops and sheltered facilities (*e.g.*, Denmark, United Kingdom, USSR). A number of countries have acted to centralise the allocation of work contracts, to issue licenses and apply standards of operation, to ensure that appropriate rehabilitation and training services are provided by qualified personnel, and to control the payment of wages. Where employers or organisations operating sheltered and special workshops pay workers less than the statutory minimum wage, this must be authorised under exception clauses of the new legislation.

Some countries have developed detailed guidelines to ensure that workshops fulfil both production-oriented functions as well as social, pedagogical and therapeutic roles. Other legislation requires that workshops should include vocational evaluation and assessment services. Workshops should, in the language of recent pertinent legislation, not be viewed as 'terminal care' facilities but should function as 'special production centres' and transitional training institutions. For the most severely disabled, who cannot meet the entry requirements of these workshops, some countries have legislated for home work schemes or for diversionary activity at occupational centres with minimal work routines.

Legislative measures have also been adopted in some countries in the past decade enabling many more persons with disabilities to benefit from special social and vocational rehabilitation services. In the past, many rehabilitation facilities and services were developed with the needs of only the physically handicapped in mind and, indeed, much of the early action on behalf of the disabled was prompted by the needs of war disabled and victims of work accidents. No doubt inspired by the United Nations Declaration of the Rights of Mentally Retarded Persons (December 1971), several countries have made special provisions for the training, placement and employment of the mentally retarded, including the creation of job opportunities in the public sector. There is a growing interest in extending rehabilitation services to the psychologically handicapped, the emotionally impaired, the socially maladjusted, the drug dependent and the alcoholics; specialised legislation has been enacted in several countries to ensure the integration or reintegration of the formerly mentally ill and the developmentally disabled. It has been recognised that persons with developmental disabilities have a right to appropriate services in the least restrictive settings which are designed to maximise their developmental potential. New legislation or amendments to existing statutes have also created specialised services for the most severely disabled, the deaf-blind and the elderly disabled. In a number of countries the national governments have established centres of research on disability and rehabilitation services. For example, the United States Rehabilitation Comprehensive Services and Developmental Disabilities Act of 1978 (amending the Rehabilitation Act of 1973) created a new programme of comprehensive independent living services for the disabled as well as a new National Institute of Handicapped Research.

Finally, perhaps one of the most important new developments from the standpoint of governmentally assured services to handicapped persons is the gradual introduction of measures to assist the disabled in rural areas. Although only a few systematic attempts have been made (*e.g.*, in Colombia, Ghana, India, Indonesia, Kenya, Malawai, Malaysia, Philippines, Tanzania) to provide extension services and to create a network of rehabilitation stations with local community workers, governmental commitment along these lines through policy decisions, public laws and decrees is a most welcome development.

The technical and administrative arrangements for bringing resettlement services to disabled rural men and women vary. Labour regulations and employment-service decrees have in some countries (*e.g.*, Ghana) stipulated the creation of disability units in local employment offices. Some countries (*e.g.*, Tanzania) are running special rural pilot projects



such as planned farming villages in which families with blind and disabled members live and work next to able-bodied families. Some public health and rural development laws contain provisions stating that local centres and workshops must be open to disabled persons. There are also examples concerning production cooperatives where provisions are made in cooperative law for disabled persons to join agricultural cooperatives (*e.g.*, in India).

### CHANGING PATTERNS IN INDUSTRIALISED COUNTRIES

In many industrialised countries, the late 1940s and 1950s were a period of consolidation, development and extension of comprehensive rehabilitation programmes which were based on new social legislation promulgated in the early postwar years.

The pattern of disability in these countries changed dramatically, however, during the same period. Whereas in the immediate postwar years the vocational and social reintegration of large numbers of persons suffering from tuberculosis presented a formidable challenge, new methods of treatment introduced in the early 1950s brought about a dramatic reduction in the numbers suffering from this disease. Subsequently, many sheltered workshops which had been developed exclusively for the tuberculous opened their doors to other categories of disabled persons.

The same advances in medical science also brought about a revolutionary change in the treatment and rehabilitation of the mentally ill. As a result, the majority of psychotic patients were no longer faced with the forbidding prospect of lifelong institutionalised care but were given the opportunity, through hospital-based rehabilitation workshops, 'half-way house' accommodation, day treatment and vocational training services, to become socially readjusted and gradually reintegrated into a normal community setting.

This deinstitutionalisation approach to the treatment and rehabilitation of the mentally ill had a marked effect on the development of vocational rehabilitation services. Whereas such services had previously been mainly concerned with the rehabilitation of the physically disabled, including a preponderance of respiratory cases, they were now faced with a sudden influx of large numbers of so-called mentally restored persons—many of whom had spent a lifetime in the sheltered confinement of a mental hospital. It was soon discovered that short-term vocational rehabilitation courses aimed at preparing the physically handicapped for a quick return to work were entirely inadequate for the psychiatrically disabled who began to account for (and still do today) as much as one-third of the case load of some vocational rehabilitation centres. The need for specialist psychiatric and psychological help in preparing the disabled for employment also became apparent. At first, too much reliance was placed on the results of intelligence testing, but this soon gave way to a more practical approach, with assessment based on a broader interpretation of psychological test results combined with observation and outcome of actual performance in a realistic work situation.

In the past two decades, much effort and thought have also been directed towards the vocational rehabilitation of the largest disability group of all—the mentally retarded. Acceptance of the rehabilitation process known as 'normalisation' has gained ground through the initiative of parent groups and non-governmental organisations, with the objective of integrating the mentally retarded in the normal community rather than hiding them away in institutional care. In many programmes, training the retarded in activities of daily living and offering them a range of social and cultural experiences now go hand-in-hand with occupational training and, although the rehabilitation process may extend over several years, quite remarkable results are being achieved in resettlement terms in both open and sheltered work settings. Some interesting examples of employment openings for the mentally retarded are described later in this part of the Report.

Technological change, especially during the 1970s, has affected the development of vocational rehabilitation services to such an extent that this subject alone merits special



consideration.

With drug and alcohol abuse reaching epidemic proportions in many countries, vocational rehabilitation services have been faced with the problem of providing readjustment and training courses for an ever-increasing number of addicts and other socially maladjusted persons. The traditional type of rehabilitation programme has proved to be ineffective for the greater majority of addicts and community, rather than institution-based, services seem to indicate the best avenue of help. A welcome development in this respect has been the growing interest of trade unions and employers' organisations, particularly in the United States and the Scandinavian countries, in sponsoring employee-recovery programmes whose aim is to provide help, through community-based services, to addicts or potential addicts, before they become dysfunctional both in social and vocational terms.

The recent recession in industrialised countries has seriously limited the placement opportunities for disabled people in the open employment market. This has resulted in more emphasis being placed on helping workers who become disabled to remain with the same employer. Moreover, the high cost of providing subsidised work in a sheltered setting has resulted in economy drives, with more attention being directed to developing sheltered workshops with a central administration on group-management lines and also to the introduction of modern management techniques and profitable subcontract work, central sales services and the integration of blind and sighted workers in the same workshop, but the idea which was fast gaining ground prior to the economic recession, *i.e.*, that rehabilitation for open employment should be a basic aim of a sheltered workshop programme, has made little headway. Unfortunately, too, in periods of high unemployment some quota schemes obliging employers to engaged disabled persons rarely fulfil the job-creation purpose for which they were intended and several countries (*e.g.*, France, Netherlands, United Kingdom) which have adopted quota schemes are relying more and more on a voluntary approach to placement coupled with incentive schemes.

A welcome development, which dates back to the late 1960s and early 1970s and which will undoubtedly inject more realism and dynamism into rehabilitation services and is already changing the pattern of their delivery for the better, is the growing awareness of the disabled themselves that they should band together, speak out and take control of their own lives and destinies. Far too often in the past, rehabilitation services have been planned and developed with little or no prior consultation with the disabled people for whom the services were intended. Indeed, it was at the insistence of the disabled themselves that the original title of the special year, "International Year for Disabled Persons", was changed to "International Year of Disabled Persons", thus indicating that the disabled should be involved and have a say in planning the Year's activities.

Just how effective the intervention of the disabled can be in determining their own destiny is clearly illustrated in a recent paper prepared by the Director of the Hong Kong Society for the Blind:

Whilst in its earlier years, the Society may have been guided by traditional concepts of blindness, it was shocked into an awareness of a new era when in the early 70s the blind workers of the Society's Workshop resorted to industrial action in order to bring their plight and frustration to the attention of both the Government and the community at large. As a result, the Hong Kong Society for the Blind was reorganised completely in 1972. The Workshop for the Blind until then had been a dumping ground for the blind who were doing dreary jobs which were not very productive and therefore yielding little income for them. It also prevented the community at large ever getting any idea of the work, skill and ability of the blind for a particular job.<sup>1\*</sup>

The new policy which evolved as a direct result of the blind workers' protest was for

\*The notes will be found at the end of the Report.





closer links between the Blind Workshop and ordinary working conditions; to transform the workshop from a charitable institution to an industrial undertaking in its own right; to create an equitable wage structure and to introduce new and more profitable production lines such as garment-making, cardboard box-making and furniture production. Such a policy could well set the pattern for many other workshops.

The need for the disabled to be involved and have their right to equal opportunity to participate fully in every aspect of society was clearly expressed at Rehabilitation International's 1980 World Rehabilitation Congress by the Director of Rehabilitation for the State of California, himself a severely disabled person, as follows:

In order to secure this right [to equal opportunity], we had to free people with disabilities from a patronising and segregating society. . . . In the past decade, we have done much to dispel the myth that persons with disabilities are weak or sick. . . . We need to help the general public understand that disability in and of itself is not devastating, and that a person who has a disability can live an active and rewarding life. . . . changing attitudes is only one part of our task; . . . As in the past, we shall face stiff opposition. We shall be confronted with so-called cost-efficiency computations to "prove" that segregated systems are less expensive.

We know, however, that this type of argument cannot stand close analysis. We know that a dollar figure cannot be placed on the increase in self-esteem which flows from living in an integrated society. Most importantly, we know that persons with disabilities will no longer accept a segregated society.<sup>2</sup>

#### CHANGING PATTERNS IN DEVELOPING COUNTRIES

If progress over the past three or four decades in helping the disabled in developing countries to become useful members of their community is to be measured in terms of improvement of the quality of life for everyone on a basis of equality and with sincere respect for the basic rights of the individual, then very little progress has been made at all. Indeed, it is true to say that in most of these countries the disabled are still the poorest of the poor and their social and vocational rehabilitation needs are still often overlooked.

Even with improving health care and disability-prevention schemes, the numbers of disabled in the developing world continue to grow at an alarming rate, and the hoped-for rapid expansion of pilot vocational rehabilitation services which the ILO has helped to establish in more than 50 countries in the past 20 years has not occurred, mainly due to lack of funds and trained staff. Most of these pilot services still cater for only limited numbers of physically disabled, blind, deaf and leprosy patients, and the social and vocational rehabilitation needs of millions of mentally ill and mentally retarded persons in the Third World are still largely unmet. Few of the pilot services have yet reached out into rural areas where 80 per cent or more of the disabled live.

Perhaps the most disturbing trend of all, however, in the Third World is the decline in the role of the family in caring for the disabled. This decline, coupled with the movement from farm to city, throws an ever-growing responsibility on local and national government to ensure the social and vocational well-being of their disabled citizens. Just how difficult this will be can be judged from the fact that the ILO estimates that some 500 million new jobs will be needed in the developing world in the next ten years for newcomers to the workforce and to eliminate existing unemployment.

There are encouraging signs, however, that developing countries are recognising the economic implications of disablement, which may mean maintaining one in ten of their population. This concern is being reflected in an increasing number of requests for ILO assistance in establishing vocational rehabilitation programmes within the context of national development plans and sometimes as a component part of larger programmes for the non-disabled, such as vocational training, labour administration, social welfare and





social security.

As in the industrialised countries, changing patterns of sheltered employment are also apparent in the Third World. The concept of sheltered workshops was originally based on the need to provide occupational activity for severely disabled people who could not compete on equal terms with workers in open employment—hence the need for subsidies to make good the losses that such workshops invariably incurred. Developing countries have very little capital available to establish sheltered workshops, let alone to meet heavy costs of maintenance and recurring losses; consequently, there is now a marked preference for the development of production workshops for the disabled that are run on the lines of small-scale industry and cooperatives—workshops which, with carefully selected production or subcontract work, can meet their own running and maintenance costs with a small surplus used for further investment and expansion.

Finally, perhaps the most important development of all affecting the pattern of rehabilitation in the developing world—albeit still on a very limited scale and in only a few countries—is the planning of social and vocational rehabilitation services at the community level with community development workers, together with aides and auxiliaries responsible for the delivery of services.

#### TECHNICAL COOPERATION

Only one or two isolated projects in the field of vocational rehabilitation were implemented by the ILO before 1955 and it was the adoption of Recommendation No. 99 that gave the impetus to technical cooperation work in this field.

The nature of the technical cooperation requested and provided has varied widely from one country to another, depending on the level of social and economic development reached, the emphasis placed on it by the requesting government, the extent of local knowledge and awareness of needs and possibilities and the financial, administrative, technical and personnel resources available. These factors govern both the scope and objectives of a project and determine how it should be tackled.

Sometimes the request has been for an initial survey of disability problems and rehabilitation possibilities or for assistance in planning the legislative and administrative framework of a vocational rehabilitation programme; at other times, the requests relate to the establishing or extension of one or more services (vocational guidance, vocational training, selective placement or sheltered employment). Help is often sought in setting up a rehabilitation centre in which some or all of the above services are provided for the disabled either as part of wider vocational rehabilitation facilities or in conjunction with medical rehabilitation services. The request may be to help a public service or a voluntary agency recognised and supported by the government. Staff training is always a most important element.

ILO policy on technical cooperation in vocational rehabilitation may be summarised as follows:

##### *Country Responsibility for Choice of Programme*

Each country should decide for itself what its most pressing needs are and what form its initial vocational rehabilitation programme should take (*i.e.*, whether to have a national or regional programme for all disabled or to concentrate on one or two major disability groups, whether vocational guidance, vocational training, special placement services, sheltered employment or a rehabilitation centre are first needed).

##### *Study of Situation a Prerequisite*

Each country's decision in this respect should be based on a study of the available statistics of disability and the number, type and characteristics of available services.



### *Scope of Vocational Rehabilitation*

Even if the initial programme is restricted to certain disabled persons only, it should be aimed at ultimately providing services for all disabled persons, whatever the origin and nature of their disability and whatever their age, provided that they can be prepared for, and have reasonable prospects of, securing and retaining suitable employment.

### *Main Objectives of Vocational Rehabilitation*

The main objectives of any vocational rehabilitation programme should be:

- (i) to demonstrate and improve the working qualities of the disabled;
- (ii) to emphasise their abilities and working capacities, not their disabilities;
- (iii) to promote working opportunities for them;
- (iv) to overcome employment discrimination against them;

and these factors should be taken into account from the beginning of any programme.

### *Satisfactory Placement*

No matter what the scope of the programme the greatest attention and emphasis must always be put on the final need for satisfactory placement in employment, *i.e.*, resettlement.

### *A Comprehensive and Continuous Process*

For each individual disabled person benefiting from it, vocational rehabilitation should be considered as one comprehensive and continuous process from the moment of identification as disabled to the time of satisfactory resettlement in employment.

### *Main Contents of a Vocational Rehabilitation Programme*

Any programme of vocational rehabilitation should provide services of vocational assessment and guidance, vocational training and selective placement in employment or sheltered employment.

### *Provided within Framework of Existing Services*

As far as practicable these special services for the disabled should be provided within the framework of and form an integral part of existing vocational guidance, vocational training and placement services.

To illustrate in a significant manner the problems encountered in establishing vocational rehabilitation services in the least developed countries, mention may be made of the report of an ILO expert, who described how he interviewed 60 people for admission to a new rural rehabilitation centre, varying in age from 16 to 35, and with only a few being literate; of the 60, 42 were crippled in every sense of this cruel word and came into the interviewing room crawling on all fours; their disabilities, from birth or early childhood, were due to a variety of causes but mainly poliomyelitis and malnutrition, which are, of course, preventable; their immediate need was for the provision of prosthetic and orthotic appliances but the nearest limb-fitting centre was more than 800 kilometres away.

Apart from the severity and extensiveness of disability in developing countries, the planning of vocational rehabilitation services has to take into account the massive unemployment and underemployment that severely curtails or prevents the placement of disabled persons in the open employment market. Consequently, much of the ILO's technical cooperation effort in the developing world has been directed to creating employment opportunities for the disabled. In both the urban and rural sectors, commercially viable production workshops for disabled persons of all categories have been successfully developed with a minimum of capital investment and often using locally available



material and supplies. One such ILO-assisted workshop in Africa for example, in co-operation with the nature conservancy authorities, was given permission to collect flamingo feathers during the moulting season from a lakeside reserve which sheltered millions of these birds. The beautifully coloured feathers were made up into brooches in the workshop and were eagerly bought by visiting tourists. The severely disabled in other workshop projects have produced chess pieces carved from local soapstone; candlesticks made from driftwood gleaned from the river bank; simple jewellery—necklaces, cufflinks and bangles—carved from local hardwoods; greeting cards made from the bark of a tree; pallets assembled from off-cuts provided free of charge by a local sawmill; protective gloves manufactured from waste material offered by a jeans-making firm; dresses and hats made from handwoven and locally printed cotton cloth. Many other workshops base their activities on subcontract work from government departments and industry, thus avoiding the need to establish costly sales services.

Admittedly, such workshops provide employment for only a small number of disabled persons, but more ambitious projects on small-scale industry lines have also been developed in the Third World. One of the most successful enterprises of this kind is the United Abilities Company in Addis Ababa. Initially launched in an old building as an umbrella assembly workshop employing 18 blind, deaf and physically disabled persons (most of whom had previously relied on begging for a living), it now provides well-paid employment for more than 400 severely disabled men and women; they in turn support some 2,000 dependents. The company has since branched out into umbrella frame and handle manufacture and the substantial profits it has made over the years have been invested in workers' welfare, as well as a new product—the manufacture of dry-cell batteries. This highly successful enterprise in small-scale industry, which was planned and established under ILO technical cooperation arrangements and subsequently developed and successfully expanded under Ethiopian management, has attracted world-wide attention. It is a project, too, which has meaningful application not only to other developing countries but also to industrialised countries looking for fresh avenues of resettlement for disabled workers. With this in mind, a brief description of the concepts and methodology applied in developing the project may be of interest.

An initial feasibility study indicated a strong potential national market for umbrellas—an article in wide use but entirely imported. Research and study of umbrella assembly showed that the process involved 15 main steps or separate job functions and that manufacturing norms, necessary raw materials and equipment were such that the work was suitable for disabled persons and could be started on a small scale with a reasonably low capital investment. Each job function was carefully examined and broken down into simpler stages (40 in all), thus allowing for a wide range of physically and mentally handicapped workers to be employed. In many cases, the disabled themselves suggested improved methods of production as they gained experience. The formal training period for some tasks was very short (two weeks), for others more prolonged (two months), depending on the intricacy of the job content and the dexterity of the trainee. The basic principle followed was job analysis, modular arrangement of the work and a division of labour among the various disabled (sighted and blind) on a team-work basis. Sections were created and supervisors were selected from the best disabled workers. Each worker was taught all the tasks in one section so that in the absence of one or more workers, bottlenecks in production could be avoided. It is interesting to note that neither the title of the company nor its product included the word 'disabled'. Customers and bulk purchasers were therefore unaware that the umbrellas had been produced by the disabled, and its sales appeal was therefore based on quality rather than sympathy. By the fourth year of operation, the company was producing 600,000 umbrellas annually—meeting all market needs in Ethiopia as well as exporting to other countries. The success of any enterprise is heavily dependent on sound management and the company had this in good measure. Indeed, it was the Ethiopian counterparts, who took over the project when the ILO expert completed his



assignment, who developed it to the peak of success it has now attained.

The United Abilities Company project clearly indicates that the system of Modules of Employable Skill (MES) developed by the ILO in the general field of vocational training can be applied successfully to a production workshop for disabled persons. Within this concept, ways in which people earn their living, or could earn a living, are carefully analysed. Combinations of skills are grouped into sets called 'useful functions'. Around each useful function can be created self-contained training packages or modular units which refer to the necessary skills, knowledge and aptitudes required to perform the function. The scope for this approach is unlimited, for modular units can be grouped in varying combinations to form modules of employable skill. Thus, training programmes can be adapted and adjusted to meet varying needs, and this flexible, diversified approach is most relevant to the situation of disabled workers who may be able to undertake only a limited range of tasks in a particular production process.

In the course of its technical cooperation activities, the ILO is sometimes requested to advise on the formulation of a model plan for a national vocational rehabilitation programme, closely coordinated with the existing health, education and social services. Unfortunately, budgetary and staff resources in developing countries are often so limited that implementation of programmes has usually to be done piecemeal rather than on comprehensive, national lines. Nevertheless, the interest and enthusiasm engendered by the International Year of Disabled Persons will no doubt encourage many countries to develop or extend services for the disabled on more ambitious lines. A model national five-year plan programme would, in effect, need to envisage the establishing and delivery of some or all of the following services and pilot projects, say in the first three years, with the final two years devoted to consolidation, extension and duplication of existing services:

- identification and registration of the disabled on a continuing basis;
- a ministerial department of vocational rehabilitation with responsibility for systematic staff training, equipping new services and supporting existing services;
- a national rehabilitation board or council on which all governmental and non-governmental rehabilitation interests are represented, together with the disabled themselves and employer and trade union representatives;
- an urban vocational assessment and work preparation centre, say for 100 disabled persons, designed to offer short courses of physical reconditioning and preparation for wage-earning employment, with associated vocational training courses to be provided in the centre and in existing training courses;
- an urban sheltered/production workshop, say for 100 severely disabled persons;
- a selective placement service for the disabled;
- a rural (community-based) vocational rehabilitation service offering courses for disabled persons in activities of daily rural living;
- a rural cooperative designed to offer a livelihood to groups of disabled workers who graduate from the rural vocational rehabilitation courses;
- a mobile rehabilitation service for disabled women to help them overcome disablement in the home;
- a mobile delivery and collection service for the distribution of raw materials to the training and sheltered workshops and the marketing of finished products.

Experience of developing such a comprehensive programme has shown that most services can be housed in existing buildings or integrated in existing training services for the general population, thus avoiding a new and costly institutionalised approach. Publicity for any new vocational rehabilitation activity also needs to be strictly controlled, for to raise the hopes of thousands of disabled persons while places exist for only a few attracts criticism and creates dependency.



## SOME RECENT ATTEMPTS TO SAFEGUARD AND CREATE JOBS FOR THE DISABLED IN INDUSTRIALISED COUNTRIES

The recent economic recession in market-economy countries has severely restricted job opportunities for disabled persons. With many firms laying off workers and unemployment at its highest peak since the depression years of the 1930s, the emphasis in some of these countries has been on safeguarding the jobs of those who become, or are at risk of becoming, disabled rather than allow them to be thrown onto a depressed employment market in which new jobs are scarce or non-existent. A good example of such an approach is provided by the so-called Adjustment Group System in Sweden. Some 200 of these groups were established in the public and private sector in 1971, mainly in offices and undertakings with at least 50 employees; they now number more than 5,000. The groups' main tasks are to work for a positive attitude towards the elderly and occupationally handicapped worker and, in particular, to propose measures to make it easier for them to retain their jobs or to be reallocated to more suitable work within the same undertaking. The Adjustment Group can consist of from three to seven persons—representatives of the employer, of the trade union and of the employment service, together, of course, with the disabled worker himself. Specialists such as factory medical officers, safety engineers, nurses, etc., may be co-opted as necessary. While the Employment Service is the driving force behind the scheme, the role of employers and trade unions in it is vital. Indeed, the scheme itself is an exercise in tripartite cooperation in the field of vocational rehabilitation of disabled workers.

A similar scheme, known as In-Plant Vocational Rehabilitation, operates in Norway and is based on a form of contract drawn up between an undertaking and the Employment Service. It provides for the formation of a rehabilitation committee composed of representatives of management, the firm's medical and personnel services, the local trade unions, and the Employment Service. Each committee is responsible for surveying the health and working capacity of all personnel, arranging, where necessary, for a change of job with the necessary training, adaptation of machines or of the workplace itself and providing any supportive medical, psychological or social help which the disabled worker may need.

In the United Kingdom, with the statutory quota scheme creating few openings for the disabled, emphasis has now been placed by the government on offering incentives to employers to engage disabled persons. Special schemes provide for grants towards the cost of adapting premises or equipment used by disabled people at work, as well as financial assistance to those employers who are able to offer a 'job trial' to disabled applicants. The disabled themselves may also qualify for financial assistance to cover additional travel costs resulting from their disability or to establish a business on their own account.

Similar incentive schemes operate in France, Japan and the Federal Republic of Germany. In the latter country, employers in both the public and private sectors who fulfil their quota obligation of disabled workers (6 per cent of their workforce) may qualify for grants ranging from 8,000 to 18,000 DM if they agree to train or employ a severely disabled person and create suitable training or working conditions for the person in question. In a six-month period of 1980, more than 8,000 severely disabled persons were placed under these arrangements. It is interesting to note that the funds for this scheme are derived from a national fund composed of fines levied on those employers who fail or are unable to reach their quota obligation.

In the United States handicapped workers receive special consideration for subsidised jobs and training positions under the Comprehensive Employment and Training Act (CETA). State and local governments receiving CETA funds are required to establish an affirmative action plan which covers the recruitment for and the training, placement and advancement of handicapped persons in CETA programmes. In the fiscal year 1979 alone, some 182,000 handicapped workers were enrolled in these programmes. The Employment and Training Administration is also providing CETA funds totalling 3.7 million dollars



to seven national organisations to serve or promote the concept of hiring handicapped workers. Among the national groups involved is the National Association for Retarded Citizens, which has subcontracts with public and private employers in 50 states to train 900 retarded persons on the job in a variety of occupations such as nursing aide, child-care attendant and kitchen helper; also Goodwill Industries, a sheltered employment organisation, which is training 550 handicapped persons in 12 cities; the Electronic Industries Foundation, which operates a national programme to promote new job opportunities for the handicapped in the electronics field; the Epilepsy Foundation of America, which is serving some 775 persons with epilepsy primarily through referral to and placement with public and private employers in jobs ranging from labourer and construction worker to insurance salesman and teacher. Participants must be handicapped, that is, have a physical or mental disability that constitutes a substantial barrier to employment, and they must be able to benefit from the services provided.

Another comparatively new employment-creation development in the field of sheltered employment is that of the 'enclave', which has been defined as a group of severely disabled people working together under special supervision in an otherwise ordinary and undifferentiated working environment. This arrangement is particularly suited to supervised groups of the mentally retarded, mentally ill and those suffering from epilepsy both in industrialised and rural settings. Packing and assembly work are among the main 'enclave' activities but such groups have also been successfully trained for park and garden maintenance and in forestry work, planting seedlings and thinning out trees. In the United Kingdom, the 'enclave' approach to providing sheltered employment for severely disabled workers is developed under the title of 'Sheltered Industrial Groups'. There is no doubt that the extension of 'enclave' arrangements would improve the resettlement prospects for greater numbers of severely disabled people. The value of the schemes lies in its close relationship to ordinary employment, and experience has shown that this type of sheltered employment enhances the morale and effectiveness of the severely disabled worker.

In Eastern European countries, cooperatives of disabled persons have provided an ideal avenue for their resettlement. In Poland, the Invalids' Cooperative Movement has a central role in providing rehabilitation and socio-vocational services. Through some 470 industrial cooperatives and associated homemaker and service-work schemes, the movement currently employs some 300,000 workers, including 200,000 physically and mentally disabled persons. This is slightly more than one-third of all disabled persons gainfully employed in Poland today. Included in this total are 50,000 homeworkers and a similar number in the cooperative 'enclave' sheltered employment groups.

The comprehensive activities of each cooperative or group of cooperatives embrace rehabilitation services for their disabled members within the context of productive work; these include 'basic rehabilitation' (individual counselling and work conditioning), on-the-job training, adaptation of tools, machinery and workplaces, regular medical and paramedical care or supervision as well as social support (assistance in providing special aids, holidays, sports, assistance with housing and transport). Industrial activities of the cooperatives cover many fields, including, electrical engineering, chemicals, garment-making, printing, leather goods, brushmaking, confectionery, plastic ware, paper clips, drawing pins and many other products. Much of the work undertaken is on a subcontract basis for state enterprises.

State support for the cooperatives is both generous and extensive and includes tax reduction, or even tax exemption in the case of those cooperatives recognised as sheltered workshops. In one cooperative, for example, the severely retarded, after careful and patient training, are working efficiently in an 'enclave' arrangement, assembling car headlamps for the state motor vehicle industry. Exclusive or priority production rights are granted by the state for some 90 products and services. With this generous state assistance, and through its own efforts, the Polish Invalids' Cooperative Movement is financially self-supporting, with profits being invested in improving existing cooperatives, establishing





new ones and conducting an active research programme. Most important of all, the disabled workers, as cooperative members in their own right, have a say in the management and development decisions affecting their own cooperative. At the European Symposium on "Work for the Disabled", held in Poland and Sweden in 1979 and sponsored by the ILO, most delegates felt that the Polish system of cooperatives of disabled persons was basically relevant and applicable to their own countries.

Another interesting development in Eastern European countries is the provision of rehabilitation services within large undertakings. In addition to offering medical treatment and medical rehabilitation to those workers who fall sick or are victims of accidents, work posts within the plant are specially selected for vocational rehabilitation purposes; a special works committee (similar to the Swedish Adjustment Group) helps to draw up a rehabilitation plan with a view to reinstating the disabled worker in his former job or in an alternative suitable one.

An innovative approach to promoting employment opportunities for disabled persons was introduced in Japan in 1972. This takes the form of an annual national skill contest of Abilympic (a contraction of the two words 'Ability' and 'Olympics', meaning 'Olympics of Ability') in which severely disabled workers compete and demonstrate their skill on set work pieces in many occupational areas, including engineering, watch and clock repairing, tailoring, architectural and machine drawing, radio and television repairing, etc. Medals and citations are awarded to the most successful competitors. This skill contest, sponsored and supported by the Japanese National Association for Employment of the Handicapped and related organisations of the government, employers and trade unions, has undoubtedly led to an increasing awareness and understanding on the part of the public in general and of employers in particular of the ability and potentiality of disabled persons to perform a wide range of skilled work. These national contests have been so successful that the organisers have decided to extend their scope to an International Abilympic which will be held in Japan in October 1981 to mark the occasion of the International Year of Disabled Persons.

Non-governmental organisations, with government support, continue to pay a vital role in promoting employment opportunities for the disabled. An outstanding example is provided by Bedford Industries in Adelaide, which from a small sheltered workshop has been developed into a highly profitable large industrial undertaking which provides comprehensive vocational rehabilitation services including assessment, training and employment for 1,000 physically and mentally disabled persons at the main plant and six subsidiaries. Activities comprise a wide range of production lines and service functions including printing, bookbinding, engineering, furniture making, food preserving and pre-fabricated houses; it also operates a large farm, motel and hotel. The latter services bring the general public into contact with the disabled workers, thus promoting social integration and better understanding of the employment potential of disabled persons.

### VOCATIONAL REHABILITATION IN RURAL AREAS

As already indicated, the great majority of disabled persons in developing countries live in rural areas. While high priority is now being given in these countries to rural development, there is little evidence to suggest that the disabled have benefited to any great extent.

Voluntary organisations were first in the field to recognise the social and vocational needs of the rural disabled, with special priority accorded to establishing isolated settlements for leprosy patients and rural rehabilitation programmes for blind persons.

The ILO's first attempts to help develop rural vocational rehabilitation programmes were confined to those areas where some basic rural infrastructure existed in the form of rural institutions, small-scale and cottage industries, labour-intensive public works and cooperatives. It soon became evident, however, that the vocational training available



through these services was often beyond the physical and mental capacity of the more severely disabled members of rural communities, many of whom had been confined to family care for many years. As a result, rural rehabilitation centres were established which offered vocational adjustment courses (to help the disabled to become accustomed to the demands of a full and often exacting rural working day) and training in rural daily living. These vocational adjustment and training courses were established in rural areas of several West and East African countries during the 1960s. They varied in length from six to twelve months and their aim was to produce not a craftsman, but a worker who could help himself and his family to obtain a living from the land. Courses were designed therefore on an 'all-round' basis to give simple basic instruction in crop growing, chicken raising, animal husbandry, home economics, hygiene and literacy. On successful completion of the course, graduates were provided with basic hand tools before returning to their home area; others banded together and formed small rural cooperatives. In most cases it was found that the rural rehabilitation centre was just as costly to run and maintain as an urban-based facility, as the centres, which often drew their clients from a large rural area, had to offer residential accommodation which is expensive to run and maintain; the varied nature of the courses themselves called for experienced instructors, who were in short supply; and the transfer of the disabled person from the shelter of his rural surroundings to a residential centre often unsettled him. Moreover, as more serious cases of disablement were admitted to the centres, it was found that they could not assimilate the full range of instruction, and the course content had to be modified considerably to meet individual and varied needs.

The planning of vocational rehabilitation facilities in rural areas of the Third World is undoubtedly faced with more imponderable and complex problems than the relatively straightforward urban-based programme. Indeed, even in the same country, there is no common denominator for what can be termed a 'rural area'. In some areas mechanised farming has resulted in social and economic transformation of village life; in others, subsistence economy prevails and the overall situation is still very much characterised by traditional life styles including a tolerant and protective approach to the weakest members of the community. In the latter areas, it is often the recognition of local customs and not the perfection of technical development that determines the success or failure of assistance projects.

The ILO's experience therefore indicates that the strategy for vocational rehabilitation programmes in rural areas must be founded on basic needs. Formal training and employment must be de-emphasised, and the term 'employment', if used at all, should signify the participation of the disabled person in any activity which contributes to meeting the basic needs of the family. In the least developed rural areas, there is every indication that the situation of disabled persons is becoming increasingly precarious. Unless an accepted role is found for them, they may find it increasingly difficult to survive, for in conditions of extreme poverty there is little to share.

The ILO, the WHO, UNESCO and UNICEF, together with a number of international non-governmental organisations, have recognised this basic-needs approach to resolving the rehabilitation needs of disabled persons in rural areas; both individually and collectively, they have recently launched a number of 'grass-roots' projects.

One such project is being carried out in Indonesia, with the ILO assisting the Department of Social Affairs in a UNDP-funded project to introduce vocational rehabilitation services in isolated areas on a low-cost, high-output basis and mobilising community efforts and responsibilities in dealing with disablement problems. Based on a thorough assessment of rehabilitation needs and feasibility studies in four rural areas selected for project implementation, several hundred persons, including ministry staff, field workers and volunteers, are being trained in the basic rehabilitation principles in preparation for delivery of services at the community level. This pilot, non-institutionalised approach is expected to provide models for nation-wide implementation.

A similar ILO-assisted approach is also under way in Ethiopia, where some 200 members





of rural workers' and youth organisations will be trained as rehabilitation aides to assist disabled persons to become socially and vocationally reintegrated in their rural community.

These and other projects are being carefully researched and are expected to have positive implications for the future delivery of rural vocational rehabilitation programmes which should include the best elements of both the institutional and community-based approaches.

Even in industrialised countries, little attempt has been made to develop vocational rehabilitation services for the disabled in rural areas. No doubt, it could be argued that there is scarcely a need for such services when farming is highly mechanised and when all the benefits of modern life reach out into even the most isolated villages. Yet the revival of traditional rural crafts and skills in many countries surely presents an interesting and satisfying employment outlet for many disabled persons.

### THE IMPACT OF NEW TECHNOLOGY

Advances in technology, the use of ever more sophisticated tools and equipment, the adoption of automated production processes and the introduction of computerised systems for service and production work have had far-reaching effects on vocational training methodology and job opportunities for disabled as for all other workers.

The employment impact of new technology, in particular the dramatic replacement of the human operator through automated equipment, often results in reduced demands for labour. It may also call for greater allround skill and adaptability on the part of the operator, and vocational rehabilitation and training programmes must take this into account so that the disabled can compete for the new job opportunities in a changing employment market. It is also true to say that automation is reducing or eliminating physical demands and safety hazards in many occupations, thus bringing more jobs within the range of the often limited capacity of physically disabled persons. On the other hand, modernisation of plant and, in particular, automated processes are responsible for making many unskilled and semi-skilled jobs obsolete, thereby increasing the need for training in new job skills. In this respect, employment opportunities for some categories of the disabled may be adversely affected, at least in the particular sectors where the changes have been introduced. For the mentally handicapped, while the acquisition of new skills or the ability to perform a complex task may be difficult to achieve, the necessary adjustment to the psycho-social demands of the change itself may well be beyond their capacity. On the other hand, there is no evidence to show that the physically handicapped as a group are less adaptable than others to the acquisition of new skills for more complex work.

There is one aspect of new technology, however, which has brought incalculable benefits for disabled persons: this relates to the application of new technology in the production of assistive devices of all kinds—mobility aids, communications systems which convert sighted signals into recognisably audible sounds for the visually impaired and conversely for deaf persons; the harnessing of rehabilitation engineering or ergonomic principles to the adaptation of tools, machines and workplaces; electronic reading and writing aids; improved prosthetic and orthotic equipment. These scientific and technical achievements have indeed widened the social and vocational horizons for many disabled persons.

It may suffice to name a few major breakthroughs. For example, in the USSR, United Kingdom and other countries, electronics experts have perfected the myo-electric hand which can be directly controlled from the brain. Out of this research and experience, even more sophisticated sensors are being developed which will permit self-controlled mobility for many thousands of paralysed persons.

The Optacon machine has opened up a whole new world of training and employment for the blind, converting as it does the printed word into tactile impulses which can be felt and 'read'. Engineers have gone even further in building electronic reading machines with a direct optical-audial conversion so that the blind can listen to a direct synthetic-speech reading of a printed text. Computers are now being used to speed up the translation



and printing of braille texts; microelectronic devices are now so advanced as to permit the employment of blind persons as computer programmers in many countries.

An ingenious piece of equipment recently developed in the United States by SRI International under a grant from the Rehabilitation Services Administration of the Health, Education and Welfare Department illustrates the tremendous progress made in developing electronic communicating aids for the sensorially handicapped. It is called the Hand-Held Telephone Terminal for the Deaf, is pocket-sized, battery-operated, and will enable many deaf persons to use the telephone. It has a 48-character alphabet/numerical keyboard arranged like a typewriter but using calculator style keys with a 16-character wide thermal printer. A deaf person wishing to make a telephone call attaches the hand-held terminal to a telephone handset. A line signal indicator lamp shows the progress of the call. A steady glow indicates a dial tone is present and the desired number can then be dialled. A slow intermittent flash indicates a ringback signal, with a much more rapid series of flashes when the line is occupied. If the party answers, a random fluttering glow indicates that the receiving party is answering by voice, while a text appears on the display panel when the party responds on a teleprinter. The two parties take turns, alternately typing and reading the reply, with each person indicating the completion of a statement with the letters 'GA' meaning 'Go ahead'.

Classroom instruction, technical teaching, access to information systems and to reference sources have been revolutionised by new technology, *e.g.*, through closed-circuit television systems, thus bringing a wider range of knowledge into general and special education and training programmes for handicapped persons.

There are several interesting examples of the severely disabled meeting the challenge of production work involving advanced technology. One of the projects operated by a spastics' organisation in Australia is an electronics factory which employs some 650 workers, including 300 disabled persons (many of whom suffer from cerebral palsy with multiple impairments). Ergonomic techniques have helped to overcome the functional problems of the disabled workers so that they are competing quite successfully with the able-bodied in producing telephone equipment.

A similar electronics project is operating in Japan under the sponsorship of Sun Industries—a leading provider of employment opportunities for the disabled.

The high cost of advanced technology for the disabled, however, remains a serious problem. Governments of some industrialised countries (*e.g.*, Federal Republic of Germany, Sweden, United States) have made substantial funds available for research and development in this field, but few of the benefits of the new technology have yet reached developing countries.

## WOMEN WITH DISABILITIES

Despite the almost total lack of international statistics concerning the situation of disabled women, it can be reasonably assumed that they account for at least one-third (or 150 million) of the total population of disabled individuals in the world today. If disabled female children are included, then the world total of female with disabilities is in the region of 225 million or approximately 5 per cent of the total population in any given country.

Social scientists have pointed out the double discrimination from which disabled women suffer: once because of their sex and once because of their disabled status. This discrimination is severe and quite pervasive in that it affects all areas of life: education, employment, economic status, marriage and family, health care and rehabilitation.

Little research has been undertaken and little literature exists on the subject of disabled women. Nevertheless, available evidence indicates that they face serious problems of access to rehabilitation programmes even in societies where such services are highly developed. As long as the potential for a return to gainful employment is a criterion crucial to the provision of rehabilitation assistance, then most disabled women will be left out.



As to employment itself, women in general face many difficulties, not the least of which is the narrow range of occupations which are open to most of them. For this reason, as the economic recession in Western Europe worsened, women experienced more difficulties in the employment market than men; if they have a handicap or disability to contend with, even greater difficulties are encountered.

In many developing countries almost all the routine and physically exacting jobs in agriculture are performed by women. Even when mechanisation is introduced, this is usually applied to tasks performed by men while new practices in ridging, hoeing and weeding impose new demands on women; and when the day's work is done, the task of running the home and caring for the family, in general, confronts them. The added burden that a disability imposes on women in such circumstances may be well-nigh unbearable.

Because of prevailing sex-role stereotypes, single, divorced and widowed women who are severely disabled and heads of households with dependent children do not receive disability-related benefits and other forms of assistance as often as men.

Many disabled women around the world face discrimination not just because they are women and disabled but also because they may be illiterate, unskilled and poor. All too frequently, disabled, poor women are deprived of all human rights and may be reduced to begging for their very existence.

Another important factor is that the prevalence of disabling chronic illnesses tends to increase with age, especially after 45 years; therefore, women, whose life expectancy is on the average longer than that of men in most societies (developed as well as developing), have higher chances of becoming disabled.

In its technical cooperation activities the ILO is doing its utmost to ensure that disabled women have a fair share of vocational rehabilitation opportunities, but the obstacles are still tremendous.

## PUBLIC ATTITUDES AND COMMUNITY PARTICIPATION

The slogan of one Canadian non-governmental organisation for the disabled states: "The handicapped, their greatest handicap may be you!". It is quite clear that rehabilitation as a process, in addition to its technical aspects, is strongly influenced by people's attitudes. When these are negative, the impact on the outcome of rehabilitation efforts can be most profound.

In a public information programme launched by one national committee set up to stimulate and coordinate activities during the International Year of Disabled Persons, it is stressed that insensitivity on the part of the general public and their inability to relate to someone with a disability constitute a major social barrier to the full integration of the disabled in all aspects of daily life. Appealing to the general public to think of the person and not the disability, the committee asked them to remember that: "Blind people don't spend their lives waiting to be taken across the road; being deaf doesn't mean being less intelligent; clear speech is usually easier to understand than someone shouting in your ear; mental illness is not usually permanent but the knowledge of past psychiatric treatment often frightens prospective employers; mentally handicapped people have as much right to everyday life and social opportunity as everyone else."<sup>3</sup> It is these and similar prejudices on the part of the public at large that make life so difficult for the disabled.

Although a certain percentage of disabled persons admittedly require special assistance in order to increase their degree of physical, vocational and social independence, it is none the less true that a majority could readily become independent and economically productive if the opportunity were provided. Similarly, a highly qualified handicapped job applicant is frequently rejected in favour of an equally qualified, or even less qualified, able-bodied applicant. One of the most frequently recurring and fundamental problems confronting persons with disabilities rests therefore on the question of equality of opportunity and thus of discrimination. It is a hopeful sign, indeed, as indicated in an earlier section of this



report, that several governments have recently adopted legislative measures in an attempt to abolish discrimination which has such adverse effects on employment opportunities for disabled persons.

But lack of opportunity may arise from other sources or causes as well. These include incorrect or incomplete information concerning the capacities of the handicapped, as well as the limited experience with this group within the context of the labour force and national development. Lack of direct contracts with disabled persons readily leads to misconceptions which leave little chance for verification and revision. Also, when employment markets experience serious under- and unemployment, it is more often the rule than the exception that the disabled employee tends to be the last hired and the first fired.

Public information campaigns have been undertaken in many countries, with varying degrees of success. At best, however, they can only be expected to complement rather than be a substitute for dynamic rehabilitation and employment programmes. In recent years, there has been a growing awareness of the great potential offered not only by smaller, community-based activities but also by seeking the direct participation of various private sectors of the community. This comes from the realisation that many governments cannot realistically hope to finance all the rehabilitation services required, nor meet the great need for staff, equipment and buildings.

Direct voluntary community participation in rehabilitation would involve a wide range of organised social, economic and cultural sectors, such as church, employers' and workers' organisations, vocational schools, the family, private individuals and groups which may assist disabled persons in making adequate social and economic adjustments. When successful, such participation can achieve the mobilisation of economically important resources of skill, manpower and material which would be beyond the financial capacity of any government to undertake on a paid or subcontract basis.

Community involvement facilitates increased contacts with the disabled and thereby broadens the possibility for greater equality of opportunity and more meaningful social integration. Moreover, the chances for the successful outcome of rehabilitation efforts are greatly enhanced if a disabled person is advised and guided by those in his community whom he knows and respects, rather than in the strange and often impersonal surroundings of a large rehabilitation centre.

## THE ROLE OF EMPLOYERS AND TRADE UNIONS

One of the most positive developments in recent years has been the growing interest of employers and trade union organisations in helping to develop, and in some cases promote, social and vocational rehabilitation services for disabled workers.

Before the introduction of legislative measures which either obliged employers in some countries to employ a certain number or quota of disabled persons or offered incentives for them to do so, the contribution made by private industry and commerce towards the vocational rehabilitation of their disabled workers depended to a large extent on the social consciousness of an individual employer or group of employers; the economic well-being of the undertaking was, as it is today, another important factor in determining the scope and magnitude of such efforts.

It was the large steel, railway, coal and automobile industries which were first in the field in developing vocational rehabilitation workshops for their sick and injured workers, albeit on a very limited scale. At the same time, many medium and even small undertakings, prior to absorption in multinational companies, often had a paternal interest in the social and vocational well-being of their workers, providing lighter and more congenial work for those who were unable to cope with heavy duties because of advancing years or disability.

There is little scope, however, in the modern industrial world for the paternal or charitable approach to vocational rehabilitation and employment of the disabled. Strangely



enough, this development has had a beneficial effect on modern rehabilitation philosophy, which aims at preparing the disabled for competitive employment and placing them on merit rather than sufferance.

As a group, however, employers and their organisations in the form of Rotary and Lions' Clubs, Chambers of Commerce and other associations, have always been conscious of the need to assist those workers whose health and livelihood are at risk. Both in the industrialised and industrialising countries, they have made important efforts and contributions to vocational rehabilitation activities, both private and non-governmental.

The one factor that has impressed employers more than any other in postwar vocational rehabilitation development is that disabled workers are good workers. But an efficient and capable disabled worker first requires vocational rehabilitation assistance to ensure that he is adequately assessed and carefully trained for a job that he can manage both physically and mentally, and which at the same time does not aggravate his disability in any way. In its turn, the vocational rehabilitation service can often be justified only if employment of some kind is available on completion of a rehabilitation course. To break through this vicious circle is one of the greatest challenges of vocational rehabilitation policy at the present time, a challenge that many employers have taken up.

A recent survey of some 1,500 disabled workers with varying and serious handicaps, employed by the largest chemical company in the United States, proved conclusively that the disabled can compete on equal and even better terms than their able-bodied counterparts. The survey showed that the company had had no increase in compensation costs and no injuries causing lost time as a result of hiring the handicapped; on the question of safety both on and off the job, 96 per cent of the handicapped employees rated average or better than the workforce at large; 91 per cent rated average or better on job performance; 93 per cent rated average or better on job stability, while 79 per cent rated average or better on attendance.

There are many examples of employers taking the initiative in promoting employment opportunities for disabled workers, often in cooperation with government and trade unions. "The handicapped person who finds a job is no longer handicapped" was the slogan recently adopted by a number of French companies to advertise the fact that they had accepted that firms have a responsibility to provide work for the disabled. One of the participating companies, a national bank, runs its own training courses for the disabled in collaboration with an organisation for the physically handicapped. Again in France, a large car manufacturing company has established a special workshop for those of its workers who are too handicapped for factory routine. Hours of work are flexible and the work is simple and congenial. The workshop, which produces all radiator caps for the firm's cars, has a special soundproof room for those workers who are sensitive to noise.

In the USSR 800 disabled workers at a huge automobile plant have been rehabilitated in the plant itself and reallocated to their jobs. This was done through a pilot project incorporating medical, ergonomic and vocational services and enjoyed a success rate of 85 per cent. The experiment is being extended to other industrial undertakings.

In the State of Maryland in the United States there are a number of Employers' Advisory Councils operating as subcommittees of the Governor's Committee to Promote Employment of the Handicapped. Members of these Councils, in collaboration with vocational rehabilitation and employment-service staff, meet regularly to interview disabled job applicants and, in many cases, offer them early placement.

The use and abuse of alcohol and drugs are having a growing impact on the workplace in many countries, causing problems with absenteeism, job performance, product quality, work output and employer-worker relations. For industry, this can mean a significant turnover and loss in trained manpower. In the United States some 2,000 firms view alcoholism and drug abuse as a socio-medical problem and have established formal rehabilitation programmes to help addicted workers.





Organised labour, from its earliest days, has been interested in the welfare and well-being of its members. This interest was reflected in many countries in the pressure brought to bear by the trade union movement for the enactment of legislation aimed at protecting workers who suffer injury on the job. Moreover, through collective bargaining, health and welfare schemes were developed to help alleviate the burden of disability not only for the disabled worker himself but also his family. Subsequently, trade unions extended their help and support to those members whose disabilities were not related to an occupational disease or industrial accident.

In the past two decades, with the realisation that cash-benefit programmes, albeit a valuable source of assistance, are not sufficient in themselves to permit their disabled members to become self-reliant, trade unions have recognised the importance of vocational rehabilitation services as a means of helping them to become productive workers again.

Trade unions are also beginning to appreciate the disability prevention aspects of such services. In other words, through the application of selective placement techniques which try to ensure that the residual capacities of the disabled worker match up to the physical and mental requirements of the job proposed, a deterioration of that worker's handicap is prevented. In some instances, trade unions have joined with management, public and private groups (as in the case of the system of Adjustment Groups in Sweden already described earlier in this report) to promote vocational rehabilitation programmes for workers who have become, or are at risk of becoming, disabled.

Some unions have taken the initiative in establishing their own vocational rehabilitation services. For example, the Amalgamated Clothing and Textile Workers' Union in the United States has developed a model union programme for handicapped workers with financial support from the Federal Rehabilitation Services Administration. The union encourages all its members to report any disability problems they may have so that it can seek appropriate help from within the undertaking or from social and rehabilitation services in the locality. Shop managers and union representatives are encouraged to work together to solve any job problems of handicapped workers, and part of the project consists of a constant educational campaign to make the entire union aware not only of disabilities but also of the abilities of handicapped workers. The union gives several reasons for its involvement in vocational rehabilitation. Apart from wishing to safeguard the health and security of their members, the union rightly emphasises that rehabilitation can keep experienced valuable workers in the active workforce; also that reduced health and disability insurance costs can help prevent depletion of union insurance funds.

The American Federation of Labor and Congress of Industrial Organizations (AFL-CIO) has a long record of achievement in supporting the needs of its disabled members. The AFL-CIO has, in fact, a well defined policy on this question which stipulates that every practical means should be used to ensure equal opportunity in employment of all qualified handicapped workers—both mentally and physically handicapped. The Federation strives to increase employment opportunities for the handicapped through collective bargaining agreements and union-management cooperation; it seeks to promote rehabilitation services and recognises the wisdom of active participation in community programmes for the handicapped and encourages its state and city bodies to take an active part in the work of committees for employment of the handicapped. It is a policy which could well serve as a model for other trade unions. In a recent proclamation, the Executive Council of the AFL-CIO stressed that it is incumbent upon the trade union movement and representatives of management to provide leadership in breaking down the prejudice against handicapped individuals that denies them the employment essential to improving their lives. Its manpower arm, the Human Resources Development Institute, has in fact been providing employment assistance to handicapped persons and other disadvantaged individuals over the past 12 years. It is currently conducting a special programme with unions and other organisations in nine major cities, the aim of which is to develop training and job opportunities for disabled persons and to encourage employers and labour



organisations to make more effective use to the talents of handicapped workers.

The Canadian Labour Congress, the United Kingdom Trades Union Congress and the West German Confederation of Trade Unions are also actively engaged in supporting and promoting measures for the rehabilitation and reintegration of disabled workers into active social and economic life. The Canadian Labour Congress at its 1978 12th Constitutional Convention endorsed an Employee Recovery Programme aimed at assisting all employees who may have personal problems (particularly those related to alcohol and drug abuse). Guidelines for the programme have been developed by trade unionists and social health consultants, in collaboration with employers and local community leaders, in what is surely a fine example of a joint labour-management-community effort to assist the disabled worker.

The West German Confederation of Trade Unions is striving to end attempts to remove disadvantaged workers from their jobs and is anxious not only to create more job opportunities for them but also to safeguard their health and to prevent disability through the humanisation of work.

The Trades Union Congress in the United Kingdom at its 1980 Annual Conference led the way in declaring full support for the aims and objectives of the IYDP by pledging to make 1981 a year of progress and improvement in the quality of life for disabled people. As one delegate remarked at the Conference: "Many in the queue of unemployed are disabled people who have not lost jobs—they have never had them."<sup>4</sup>

But it is not only trade unions in the Western world that are actively supporting vocational rehabilitation activities. At its Third Congress (Mogadiscio, October 1980), the Organisation of African Trade Union Unity (OATUU), in a unanimously adopted resolution, called on its members as well as the Organisation of African Unity, the Economic Commission for Africa, the ILO and other organisations to give all possible support to various programmes in Africa aimed at the social and vocational rehabilitation and reintegration of disabled people.

While it may be argued that assistance to the disabled in general is a public responsibility, the full involvement and cooperation of management and labour in the vocational rehabilitation of disabled persons, both newcomers to employment and those in the workforce itself, is vitally essential. However efficient vocational rehabilitation services may be, both in the public and private sector, little real progress will be made in attaining the ultimate aim of these services (the satisfactory resettlement of the disabled in suitable work) without the full cooperation of both sides of industry.

## VOCATIONAL REHABILITATION AND SOCIAL SECURITY

One of the basic objectives of social security is to facilitate medical, vocational and social rehabilitation of disabled persons, irrespective of the origin of their disability. Indeed in many countries of the world social security schemes participate in the provision of medical care and rehabilitation services to the disabled, in addition to the payment of cash benefits for their income security. Even where vocational rehabilitation services provided to social security beneficiaries are not regarded as being of right, they are often considered as an investment on account of the considerable savings on benefits which can result from the successful rehabilitation of the disabled and their reintegration into active working life.

One of the essential problems facing social security policymakers is whether the scheme should organise and establish its own vocational rehabilitation services or rely on existing services provided outside the scheme itself. Much, of course, depends on the adequacy and availability of existing services. The major advantage of special vocational rehabilitation services provided by a social security organisation itself is that disabled persons covered by the scheme can be referred to them without the delay and administrative formalities which reference to an outside scheme may entail. It can be argued that such





services discriminate between beneficiaries of the scheme and those disabled persons who are not covered by it. It is, however, expected that vocational rehabilitation services established within the context of social security in developing countries, once firmly established, should be made available to both covered and non-covered applicants. Indeed, there are several examples where a social security vocational rehabilitation service has paved the way and provided the inspiration for the development of a national programme.

Social security schemes in some countries assess disability benefits on the basis of loss of earning or working capacity, while others base their assessments on the extent of the loss of faculty. With the rapid advancement in recent years in medical and vocational rehabilitation techniques (*i.e.*, the restoration of lost functions, the provision of electronic and other special aids to daily living and employment, the adaptation of tools and machines, etc.), it has become increasingly difficult to determine loss of earning capacity before rehabilitation takes place. Indeed, when—through vocational rehabilitation services—a severely disabled person is placed in gainful employment, the relationship of physical incapacity to the loss or reduction of earning capacity becomes even harder to define. An important problem here is whether or not the cash social security benefit should be reduced or suspended, if after rehabilitation a person returns to gainful work with less than the expected loss of earnings or without any loss of earnings at all. Thus, in some countries, such as the Federal Republic of Germany, Switzerland and Yugoslavia, the principle of “rehabilitation prior to benefit” has been adopted—a benefit in respect of reduced earning capacity is not granted until rehabilitation measures have been carried out. This principle has also been adopted by a Study Group on Rehabilitation which met on the occasion of the XIXth General Assembly of the International Social Security Association.

On the other hand there is the concept which takes account of the personal efforts of the disabled person to restore his working capacity. If such efforts were to result in a reduction in cash benefits, there might well be a temptation to prolong the non-working period; one could argue therefore that there should be no downward assessment of the benefit upon a review of permanent disability benefit. Thus we find in some countries (*e.g.*, Japan and the United Kingdom) that employment injury benefits are paid to the persons concerned irrespective of earnings from the new job in which they are placed after successful rehabilitation. In the United States it was suggested that there should be two types of benefits: permanent impairment benefit and permanent disability benefit, with possible entitlement to both benefits. The former may have a lifetime effect and there may not be a linkage between the value of benefit and the disabled person's own earnings. The latter may, however, be based on actual loss of earnings. There may, of course, be practical difficulties in the legislation and its implementation to this effect, but it would appear worthwhile to examine this proposal, in order to offer some solutions to the conflict between the two different schools of thought concerning social security benefits and vocational rehabilitation.

No efforts to organise and implement rehabilitation services within the context of or in association with social security schemes can succeed without the interest and cooperation of the disabled themselves. In this connection, it may be necessary to inform them, through various education programmes, of the availability and advantages of such services as well as to provide adequate income maintenance during the period of treatment and rehabilitation. There may be those, however, who are reluctant to take advantage of the services, particularly if practical difficulties exist in availing themselves of such services. Thus, it is often necessary to provide additional payments to encourage the disabled to accept the available services. Such additional benefits include, for example, travel costs, the costs of special clothing and equipment, books, allowances for an escort to the rehabilitation centre, examination fees, social security contributions, etc.

Realising the important connection between the aims of social security schemes and those of vocational rehabilitation services, the ILO gives high priority to developing such services within the context of existing or planned social insurance schemes. In Latin



America, for example, the ILO has been pleased to be associated with the excellent rehabilitation services which had been developed by social security organisations in Brazil, Mexico and Venezuela. In some countries of Africa and Asia too (e.g., Fiji, Philippines, Thailand and Zambia), vocational rehabilitation services are being planned or operated with funds provided through employment-injury benefit schemes.

It is hoped that in these countries and elsewhere social security benefits, both in cash and kind, will serve as a positive complement to the idea of support for self-help, self-reliance and the fullest development of residual abilities which is inherent in all vocational rehabilitation activities.

### THE ECONOMICS OF VOCATIONAL REHABILITATION

With the downturn in the economy in most industrialised countries and the lack of resources for social programmes in the Third World, programme planners are looking more closely into the cost effectiveness of vocational rehabilitation services. Unfortunately, many such exercises take into account only the capital cost of buildings, equipment and facilities and the recurring costs of rehabilitation staff and support personnel; the hidden costs of disability which may have lifelong implications for the disabled person, his family and the community are either ignored or given little weight. Admittedly, initial development costs may be high but one thing is certain: disability will create a cost to society regardless of whether or not adequate rehabilitation services exist. The question might also be asked as to how one can measure in terms of cost such intangibles as the feelings of well-being and satisfaction that a disabled person experiences when becoming independent through productive work. As one rehabilitation specialist recently remarked, the cumulative effects of human gains from rehabilitation become social gains for society as a whole.

A recent research study undertaken by Rehabilitation International concluded that the production benefits of rehabilitation (*i.e.*, those benefits which add to the national output) have been demonstrated in all countries of the world, including those with market and centrally planned economies, as well as developing countries. In general, it has been clearly demonstrated that vocational rehabilitation of the disabled can add to the national product through the individual disabled person who is placed in productive employment. There is not only the increase in his lifetime earnings but also his tax payments and the savings on social security benefits, including sickness and invalidity payments which, without rehabilitation efforts, he and his dependants might receive throughout his lifetime. A nation may thus regain the costs of its rehabilitation services in a comparatively short period (say 3 to 5 years) whereas the disabled worker may be productive for as long as 30 or 40 years.

Other research projects on the cost effectiveness of rehabilitation have been equally positive. For example, it has been calculated that a reduction of only one day in the average length of stay of patients in a Dublin hospital through the provision of rehabilitation services could result in annual savings of £1 million.

A study on the costs and benefits of sheltered employment was carried out in the United Kingdom in 1978 and this showed that in terms of resources there was a net benefit in the case of most workshops, without attaching any monetary values to the social benefits. Even in terms of financial costs, there was a net cost to public funds of only £2.8 million, compared with gross costs quoted of £14 million. Another sheltered workshop study in the United Kingdom conducted about the same time showed a very considerable flow-back to the Exchequer, with an average gain to the latter of £35 per worker, comprising £13 from income tax and national insurance payment and £22 from social security benefits which would otherwise have been paid.<sup>5</sup>

Similar studies have been conducted in Ireland and the United States and have reached similar conclusions. For example, following a recent audit of the accounts of the Irish Rehabilitation Institute, it was estimated that for every £1 which the state spent on support-



ing the services in 1974, £1.82 accrued to the state by means of direct revenue through taxes and social welfare savings. Another study at the same Institute showed that the cost of rehabilitating and training 100 disabled persons in 1972/73 was £69,123. For this expenditure, the gross national product of the nation benefited by £1,660,000 through the increase in the net present value of the lifetime earnings of the group (*i.e.*, net present value of lifetime earnings after training estimated at £1,881,000 compared with net present value of lifetime earnings before the training of £221,000).

The examples of the Ethiopian umbrella factory for the disabled and the Polish Invalids' Cooperatives referred to earlier show that employment projects for the severely disabled can be profitably conducted without continuous state subsidies. Another case in point is that of the 400 training and production centres of the Associations of the Blind of the USSR which cover their running and production costs so well that they refuse the state subsidy to which they are entitled. For example, one of its workshops producing electric motors on the outskirts of Moscow with some 700 employees, including 400 who are blind, had sales worth US \$5,500,000 in 1973 of which \$900,000 was profit. The profit is invested largely in social facilities and accommodation.

In the United States similar data collected on the pre- and post-rehabilitation earnings of disabled persons showed that between 1957 and 1967 the percentage of rehabilitees receiving public assistance on entry into training ranged from 12 to 13 per cent. On completion of the courses, this was reduced on average to between 5 and 6 per cent. The annual reduction in public assistance payments as a result of the federally funded state vocational rehabilitation programmes was \$9.6 million in 1961; by 1967 this had risen to \$16.4 million. These savings were considered to be an underestimation of the total reduction in the value of the care and maintenance needed by the rehabilitees, 170,000 of whom were rehabilitated in 1967 alone.

Other studies carried out in the United States are equally convincing. For example, the United States Department of Labour has estimated that for every dollar spent on rehabilitating a disabled person his lifetime earnings are increased by \$35, part of which is paid back in federal and state taxes. Yet another study showed that the employment of 100,000 disabled persons in the United States adds at least \$500 million per year to the gross national product.

The overall conclusion of such findings is that the general conception that vocational rehabilitation is a costly means of fulfilling a necessary social need—that of providing employment for severely disabled persons—is a gross oversimplification, although it must be admitted that the social, cultural and economic context in which it is undertaken has an important bearing on the outcome.

### LEADS FOR THE FUTURE

The years ahead present an unparalleled opportunity for governments, employers, trade unions and the public at large to help disabled people and improve their quality of life. The aims and the objectives of the International Year of Disabled Persons and the long-term programme of action associated with it will surely provide the framework for such assistance. Equally important is the *Charter for the 80s* drawn up by a World Planning Group of Rehabilitation International and adopted by that organisation's assembly as a major contribution to the IYDP. This charter states, *inter alia*, that: "The knowledge and skills now exist to enable each country to remove the barriers which exclude people with disabilities from the life of its communities. It is possible for every nation to open all of its institutions and systems to all people.... A nation failing to respond to this challenge fails to realise its true worth". It calls on all countries of the world to prepare a comprehensive national plan for the prevention of disability and impairment; to ensure that every disabled person and his family receive whatever rehabilitation services and other support and assistance may be needed to reduce the handicapping effects of disability so as to enable



them to lead a full life; to ensure the fullest possible integration of and equal participation by disabled people in all aspects of community life and, finally, to increase public knowledge and awareness of people with disabilities and their potential.

The ILO will do its utmost to support and achieve the aims and objectives of the IYDP and the *Charter of the 80s*. It is suggested, too, that each ILO member State should stress these aims and objectives as a starting point for a critical examination of the situation of disabled men and women in their respective countries and take concrete, positive action to improve their prospects for the fullest possible integration into active social and economic life.

In the first instance, this may call for a review of existing legislation aimed at abolishing discrimination and ensuring the rights of the disabled to an equal share of employment opportunities. The effectiveness of quota schemes and similar legislation needs to be controlled, loopholes closed and non-compliance penalties overhauled. Where quotas are simply not workable or not appropriate, other means of creating employment of the disabled should be considered, including the incentive schemes and production and co-operative workshop projects as described in this report.

There also appears to be an urgent need for greater standardisation of the definition of the many terms—'handicapped person,' 'disablement,' 'disabled person,' 'incapacity,' 'impairment'—which are often used to determine eligibility for admission to vocational rehabilitation services and receipt of benefits. Far too often such definitions emphasise the degree of disability rather than residual ability. While recognising that varying political, cultural and social factors may militate against the standardisation of rehabilitation terminology, member States might be well advised to examine the validity of their current definitions, exchange information on the subject with other countries in their regions and make any necessary revisions which would encourage and facilitate the entry of disabled persons into vocational rehabilitation services and employment. Such action could also result in the wider accessibility of services for disabled persons from different countries and stimulate the establishing of regional vocational rehabilitation facilities. With the call for more leisure and the decreasing number of job opportunities in depressed employment-market situations, the possibility of organising more part-time employment for the disabled might also be considered.

While recognising the cost effectiveness of vocational rehabilitation services in both the medium and the long term, some Third World countries may still hesitate to allocate development funds for the initial establishment or expansion of these services on the grounds that institution-building and the equipment and staff which go with it are far too costly an outlay. This would, however, be an investment in human resources, and while some institutionalised vocational rehabilitation services are essential to demonstrate pilot projects and as a base for the training of specialised staff as well as for research, the extension of services to rural areas could be conceived on more modest lines, making the fullest possible use of the existing infrastructure and community resources as evidenced by ILO project experiences in Africa, Asia and Latin America.

Some may argue, of course, that providing jobs for the disabled is still more expensive and less cost-effective than providing them for the able-bodied: that the dramatic employment situation in the world and the increasingly fierce competition for jobs makes it necessary to focus attention on those unemployed or underemployed who do not need special rehabilitation measures to become employable. Here again we come back to the basic question of human rights, and equality of access of the disabled to employment and training is surely as important a social objective as full employment itself. Moreover, if more countries were to plan and develop their vocational rehabilitation services within the context of overall employment and training policy, some of the discrimination which severely restricts the access of disabled persons to the employment market would be avoided. In the latter connection it is perhaps appropriate to quote the Declaration of Principles and Programme of Action adopted by the Tripartite World Conference on Employment, Income



Distribution and Social Progress and the International Division of Labour which met in Geneva in June 1976, which states, in paragraph 17: "In the implementation of basic-needs strategies, there should be no discrimination against the young, the aged or the handicapped."

The need to make good the serious shortage of trained staff for vocational rehabilitation programmes in developing countries presents a stern challenge during the eighties. The ILO will continue to support the training of specialised staff through international fellowship arrangements but staff shortages are of such a magnitude that other training means must be devised. Aides, auxiliaries, and volunteers can help to fill the gap but, in addition, there is an urgent need for some of the more advanced and well established vocational rehabilitation centres in the Third World to provide regional and subregional staff training facilities and to offer their expertise and experience for the training of staff from neighbouring countries. Unfortunately, there are only one or two countries in the world which offer career prospects, based on university qualifications, to vocational rehabilitation staff. The introduction of vocational rehabilitation as a subject in the curricula of more colleges and universities is surely a future priority.

In the years ahead, it is employers and trade unions who will largely determine to what extent employment opportunities for the disabled are expanded. The success of rehabilitation policies will depend critically on the extent to which they cooperate with the authorities responsible for vocational rehabilitation of the disabled and do everything within their power to ensure that disabled applicants for employment are considered on an equal footing with the non-disabled applicant. There are other more specific actions which employers and trade unions might take, either individually or jointly, to assist workers with disabilities, for example by serving on local and national disablement advisory committees, policy-making bodies and training selection panels, thus ensuring that plans for the training and employment of disabled persons match up to existing and projected industrial conditions and requirements. The experiences with employee recovery programmes and sheltered employment 'enclave' projects mentioned above should inspire many other undertakings and trade unions to take similar direct action for the benefit of their sick and impaired workers. The removal of architectural barriers at the place of work, the adaptation of jobs and machines, the safeguarding to the working environment—all such action would help to create more training and job opportunities for disabled workers. The inclusion of workers with disabilities in workers' councils and staff welfare committees would also help ensure that realism is injected into discussions dealing with problems of engaging or re-allocating workers with disabilities; and, lastly, more thought needs to be given to the rehabilitation, training and employment needs and claims of disabled workers during collective bargaining.

The perennial problem of lack of coordination in overall rehabilitation activity still continues to hinder the full development of vocational rehabilitation services. Far too often we hear that a handicapped person is referred to as a medical or social problem. We find lack of coordination between the educational, medical and vocational rehabilitation sectors, with specialised interests failing to recognise that the final objective of all rehabilitation activity is full integration of the handicapped into all aspects of community life. It is to be hoped that the national action committees which have been specially constituted in many countries to further the aims of the IYDP will look closely into this pressing problem both in the short and long term.

Here it is perhaps useful to cite the major objectives and plans of two national IYDP committees which not only make adequate provision for coordination but also lay the groundwork for continuing action and activities in the 1980s in sharply contrasting situations and settings; they may well provide useful leads for other countries to follow. The Federal Inter-Agency IYDP Committee in the United States which consists of representatives from 25 federal departments, agencies, offices and commissions, the Executive Office of the President and the United States Mission to the United Nations, has established



five major objectives:

- Furtherance of the development of a US policy on disability that will maximise coordination and minimise conflict and overlap in federal policies and programmes dealing with disability.
- Promotion of research, demonstration, service delivery, policy, and planning activities throughout the federal government that are directed toward improving the quality of life for individuals with disabilities.
- Development of an awareness throughout the federal government of the needs of people with disabilities—and the application of this awareness in the planning, implementation and assessment of all federal programmes that impact upon these people.
- Furtherance of the development and implementation of programmes to educate and inform the public and private sectors of the rights of disabled persons to participate in and contribute fully to society.
- Fostering the implementation of human rights.<sup>6</sup>

The National IYDP Committee of India also lays stress on a coordinated national plan with the main focus on developing services for the disabled child and on employment. Other programmes which will be structured around these two pivotal points will include disability prevention, vocational training and employment, research, rural rehabilitation, advocacy through legislation, the building of a data base and information system to sensitise the public about the capabilities and skills of the disabled. The plan also provides for the encouraging and strengthening of the institutional network, the building up of four national institutes in the areas of visual, orthopaedic, mental retardation and hearing handicaps. It is also proposed to encourage and strengthen non-governmental agencies.

In conclusion, while it is true to say that past efforts in vocational rehabilitation have achieved some good results, the great problem of providing employment for the majority of the world's disabled people largely remains unsolved. The unemployment situation in the world as a whole continues to deteriorate; the competition for jobs becomes fiercer; subsidies for social support systems are being curtailed. I am pleased therefore that the Governing Body has decided to include the subject of vocational rehabilitation of the disabled in the agenda of the 1982 Session of the Conference with a view to formulating in 1983 an instrument to supplement the existing instrument (Recommendation 99). Such a supplement will, I hope, point the way to the creation of new employment opportunities for disabled persons. It is indeed more important than ever for us all to recognise that what counts is the ability, not the disability, of disabled persons.



## NOTES

1. Christoffel Blindenmission, *Without Holding Hands*, Bensheim, Federal Republic of Germany, 1st edition, Jan. 1979, p. 54.
2. *International Review*, New York, Rehabilitation International, No. 3, 1980.
3. *The Disabled are People*, brochure published by IYDP England, London.
4. *The Blind Advocate*, London, The National League of the Blind and Disabled, Vol. LI, No. 703, Oct. 1980.
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6. *American Rehabilitation*, Washington DC, July-Aug. 1980.





## DISABILITIES CAN BE PREVENTED

Every year an estimated 50 million accidents occur in industry alone throughout the world—about 160,000 each day. Some of these mishaps are fatal and many leave their victims disabled for life. Millions of other people are incapacitated by crippling diseases contracted at the workplace. Society—and workers in particular—is thus paying a heavy price for industrialisation in physical suffering and economic loss.

Persons who are handicapped through an occupational accident or disease are distressing proof of insufficient safety and health measures at work. A comprehensive effort to prevent job-related disabilities is the obligation of modern industrial society and calls for greater emphasis on occupational safety and health.

Undoubtedly progress is being made in designing and applying more measures to improve the safety of the working environment, and safety performance is often remarkably high in some individual establishments. Considerable information has been accumulated concerning preventive measures and in several countries there has been a recent decrease in the number of fatal accidents at work.

—ERIC HELLEN, *Chief of the  
ILO's Occupational Safety  
and Health Branch, Geneva.*

## COMBATING ALCOHOLISM IN INDUSTRY

Alcoholism among employees costs industry tens of billions of dollars every year and more often than not is a reason for dismissal. Moreover, for every person with a serious drinking problem there are usually several family members who suffer from its effects.

Edward Sackstein, of the Vocational Rehabilitation Section of the International Labour Office, points out that "Industry is understandably concerned at the extent of alcoholism among its employees. It is not just the financial loss itself that is worrisome, but what lies behind it—more days taken off the job, illness, lower productive capacity, poorer work quality and tenser relations with colleagues."

Since two-thirds of alcoholics are already employed, they increase the risks of accidents at work for themselves and their workmates. More accidents mean injuries as well as damage to materials or machines, all of which affect the workplace. But the most distressing result of alcoholism is the sheer waste of human potential if no services are available to help the problem drinker.

—ILO, Geneva.

# The Handicapped

## A Select Bibliography

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